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Disagreement in the parent-physician relationship and control of childhood asthma.

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DISAGREEMENT IN THE PARENT-PHYSICIAN RELATIONSHIP AND CONTROL OF CHILDHOOD ASTHMA

A Dissertation Presented

by

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ABSTRACT

DISAGREEMENT IN THE PARENT-PHYSICIAN RELATIONSHIP AND CONTROL OF CHILDHOOD ASTHMA

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This study explored Disagreement in the parent-physician relationship in ideas about a child's asthma and its course of treatment as a potential cause of the difficulty for parents in maintaining control of the child's asthma at home. The study objectives were: (1) to measure 5 Types of Disagreement in 9 potential Areas of Disagreement, and (2) to determine whether Disagreement is related to control of the child's asthma. 12 physicians and 59 parents (one parent from each family), forming 59 parent-physician pairs, participated in the study. The 5 Types of Disagreement measured were Observed, Parent Perceived, Physician Perceived, Parent Inaccuracy, and Physician Inaccuracy. The 9 Areas of Disagreement studied were: (1) Causes of The Asthma, (2) Triggers to Asthmatic Symptoms, (3) Approaches to Treatment, (4) Qualitative Measure of Control, (5) Future Expectations, (6) Severity of The Asthma, (7)

Quantitative Measure of Control (8) Type of Parent-Physician Relationship, and (9) Satisfaction with The Parent-Physician Relationship. The Areas for each Type of Disagreement found to be more common in the parent-physician relationships than the others, are for Observed Disagreement: Areas 4, 6, 7, and 8; for Parent Perceived Disagreement: Area 7; for Physician Perceived Disagreement: Area 9; for Parent Inaccuracy: Area 7; and for Physician Inaccuracy: Areas 4, 7, and 8.

A comparison was made between the pairs whose children's asthma was "out of control" and those whose children's asthma was "in control". Types of Disagreement in the parent - physician relationship found to be significantly related to poor control of a child's asthma are, for Area 1: Observed, Parent Inaccuracy, and Physician Inaccuracy; for Area 2: Observed and Physician Inaccuracy; in Area 4: Observed and Parent Inaccuracy; in Area 6: Physician Perceived, Parent Inaccuracy, and Physician Inaccuracy; in Area 7: Parent Inaccuracy; in Area 8: Parent Perception and Physician Perception; and in Area 9: Observed and Parent Inaccuracy. This research suggests that clear communication of ideas about the child's asthma in the parent-physician relationship is an important influence on outcome of the asthma.

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CHAPTER 1

INTRODUCTION

Asthma has been diagnosed in somewhere between ten and fifteen million Americans at present and, according to the National Center for Health Statistics, 3,880 Americans died of asthma in 1985, which is twice the number of deaths reported in 1975 (Newsweek, March 21, 1988). In 1980, the death rate from asthma had increased to 1.3 per 100,000, which was the greatest increase in thirty-three years (Pediatrics in Review, 1988). Approximately five percent of children in this country are affected by this disease, particularly males, Blacks, and Hispanics under twelve years of age (Hen, 1986). Asthma "causes more hospital admissions, more visits to hospital emergency rooms and more school absences than any other chronic disease of childhood" (Plaut, 1984, p. 10). Hospitalizations for children under 17 years of age rose 4.5% per year from 1979-1987 (Pediatric News, 1991).

Most medical experts agree that modern medical technology is capable of effectively treating most cases of asthma. The rise in morbidity and mortality rates for childhood asthma is not well accounted for, but hypothesized explanations in the literature are

compliance, adjustment to the illness, impact of the illness on the family, poor medical care for some populations, and low levels of functioning for others (Rachelefsky, 1987). The influence of environment is usually considered as allergens or pollutants, and recommendations are often made to parents to alter these variables with expensive air conditioners, or by moving, but families' finances are not always able to support these recommendations. In addition to family resources, our societal structure unfairly segregates those who have from those who have not: Dr. Floyd Malveaux, director of the Urban Asthma and Allergy Center in Baltimore identified "inner city black kids" as not "receiving proper (medical) care" (Newsweek, March 21, 1988). Many of these factors are possible sources of conflict in the relationship between the child's parents and the child's physician.

Brody (1988) reports on the common myths about asthma that are thought by experts in the medical profession to interfere with effective treatment, including misinformation about the severity of the disease, about side effects of the medications used, and about the causes of the asthma. Many people believe it to be a psychological disorder and tend to underreact to its symptoms. Brody further cites experts who add that many physicians are treating asthma without up-to-date

knowledge of modern treatment protocol. "Furthermore, more than half of asthma care is delivered in hospital emergency rooms, where acute attacks are treated but little attention is paid to preventing future attacks and developing a treatment plan that can minimize the severity of the disease (Malveaux, p. 6)".

The challenge and intrigue of treating asthma in children is not new to research. Psychologists, psychiatrists, and pediatricians have been exploring the relationship between asthma and psychological factors for several decades. While a good deal has been written on the impact of asthma and other chronic diseases of childhood on the family, the converse is rare. In a review of the research (Campbell, 1986) on the family's impact on health, asthma was one of the physical illnesses addressed, although briefly. Campbell explained that, because asthma has been widely considered to be a "psychomatic" disease, meaning "somatic expressions of internal conflicts and unexpressed emotions" (Campbell, p. 160), a good deal of the earlier literature has been from a psychodynamic perspective. He added there have been too few studies on the impact of the family on an asthma to draw any general conclusions, other than one from Lask and Matthew (1979), which "suggests that family therapy is effective in the treatment of asthma"

(Campbell, 1986, p. 162), as a well functioning family is an important partner in the management team.

Liebman, Minuchin, Rosman, and Baker (1976) have observed, in their clinical work, "that the parents of patients with chronic, severe asthma tend to be people who are intrinsically overdependent, especially on physicians (p. 310). Liebman, et al., have described a recursive pattern in which families imbue the physician with magical powers to cure their child, the physician becomes overinvolved in this role and is unsuccessful, and the asthma becomes chronic and severe.

Few studies have explored the larger system level of childhood asthma. Imber-Black (1986) states, "...drawing a boundary around the nuclear or even the extended family as a unit of assessment and intervention is a political act that omits the contributions of larger systems and the wider social context to the development and perpetuation of dysfunction and suffering" (p. 33). The finding that suggests that family therapy is an effective tool in the treatment of childhood asthma should imply neither that the family is to blame nor that the family is the only level on which to intervene. The child, her/his parents, and the health care providers together comprise an interactive system in which the asthma is the focus. This system is another level for the researcher

to investigate, another level on which the clinician might intervene.

A leading expert in medical anthropology research, Arthur Kleinman has explored the "health-care system" in-depth.

> The health care system is a concept, not an entity; it is a conceptual model held by the researcher. The researcher derives this model in part by coming to understand how the actors in a particular social setting think about health care. Their beliefs about sickness, and their expectations and evalutations of particular kinds of care help the investigator put together a model of their system of health care. (Kleinman, 1980, p. 25-26)

Kleinman (1980; 1978) suggests that discrepant views of health care among the health care system participants is likely to negatively influence the course of health or illness. This study will compare the views of parents and physicians caring for the child with asthma and look for an association between discrepant views and control of the asthma.

Finally, the direction of this study was influenced by Systems Theory, in which mutual causality is a main concept, rather than a linear cause-effect concept, in which blame is often the outcome. Each part or member of a system or group both influences and is influenced by the other parts or members. Articulation of any point in a system as either a cause of behavior or a potential place for change is an arbitrary punctuation. Change can occur at any point in the system. This investigator's

choice of the physician-parent relationship is made because it is viewed as an important resource for change in the problem of control of a child's asthma which has not been well explored in the literature.

Rationale

Exploration of the parent-physician relationship distinguishes this study from most others. While some have included this system as part of their research, few have given it full attention.

An importance of this study lies in the approach to gaining some understanding of the problem of control of the asthma from the ideas of the persons involved in managing the condition. The physician and parent(s) are considered equal partners and, therefore, equal importance is given to the ideas of both. Other studies have often relied on the professionals' observations as the only information.

Another point that distinguishes this study from other studies, is that the subjects are still alive. Many of the studies in the literature are retrospective accounts of children who have died from a severe episode of asthma.

Also important, is the environment of the ongoing health care relationship, where the persons involved attempt to maintain the asthma condition in "control",

attempting to minimize symptoms. Again, many studies have been conducted in the hospital, when the asthma is already "out of control".

Statement of The Problem

The problem for the study is the difficulty in controlling asthma in some children with asthma. A review of the literature suggests that conflict in the relationship between parents and physicians is a contributing factor to chronicity and/or death in children with asthma. The findings are not well supported, and the nature of the conflict/disagreement is not well explored. Research on the more general issue of health care (Kleinman, 1980; 1978) suggests that discrepant views of health care among the health care system participants is likely to negatively influence the course of health or illness (p. 114). This research is concerned with disagreement between physicians and parents of children with asthma in the joint task of maintaining control of the asthma.

The researcher was interested whether Disagreement could be found between physicians and parents of children with asthma about the asthma in nine particular issues (see Data Collection Instrument, in Chapter Three) and whether the variable of Disagreement is related to the variable of control of the child's asthma.

Statement of The Purpose

The questions for this study on childhood asthma are as follows.

(1) What are the areas of Disagreement between the parent and physician who are responsible for the child's asthma care;

(2) Are discrepant views between the parent(s) and physician who are responsible for a child's asthma care associated with poor control of the child's asthma condition?

Research Objectives/Hypothesis

(1) What are the percentages of each type of Disagreement in the primary care parent - physician pair for each of the nine areas listed under Data Collection, Chapter Three.

(2) Test the following alternative hypothesis:

Ha: When a group of children aged one through twenty years whose asthma is in control and a group of similarly-aged children whose asthma is not in control, are compared for presence of Disagreement in each primary care parent - physician pair, the groups will differ, for each of the nine substantive areas, on at least one of the following measures: Parent Perceived Disagreement,

Physician Perceived Disagreement, Observed Disagreement, Parent Inaccuracy of Perceptions, or Physician Inaccuracy of Perceptions.

Assumptions

The researcher presumed that, although a child may gradually or eventually take charge of her/his own asthma care, the parents assume overall responsibility for the child's asthma care, hence, parents were focused on, rather than the person with the asthma, for the exploration of Disagreement with the physician;

That one parent assumes primary responsibility responsibility for management of the asthma, and hence, that parent was asked to participate in the study;

That the child has a primary care physician who oversees the medical management of the child's asthma, and hence this physician was asked to participate;

That there is disagreement in any relationship, therefore the variable of Disagreement has relative, rather than absolute value; and

That a person's behavior is influenced by the meaning she/he assigns to her/his situation and, therefore, ideas were solicited in the questionnaire.

CHAPTER 2

REVIEW OF THE LITERATURE

This literature review focuses on the research of children with asthma in the context of conflict or disagreement between the parents and physician in the health care system in which they are treated.

The literature review begins with a brief account ofthe historical development of the research on contextual factors in childhood asthma from the 50's to the present. Second, some of the current medical issues are presented. Finally, a critical review of th research on conflict or disagreement in the relationship between parents and the physician of the child with asthma, and whether such disagreement is related to control of the asthmatic condition is presented.

Historical Development of Systemic Research on Childhood Asthma

Research on childhood asthma began with the individual, at first physiologically alone and then psychologically, and gradually moved to the child with asthma in the context of her/his relationships in an overall attempt to explain the problem of control of the asthma. The first relationship to be explored was the mother-child relationship, as reflected the more general

psychological thought at the time. Later, researchers looked at the attitudes of parents toward their children with asthma. More recently, family dynamics were explored to account for the asthma. Most recently, some researchers are beginning to look at the relationship between the child's asthma and the health-care system in which she/he is being treated.

Some of the earliest studies on childhood asthma were prompted by the repeated observation that children with severe asthma were usually relieved of their symptoms by hospitalization, even though the same medications were administered in the hospital as at home, and that the children resumed a symtomatic state when they returned home (Purcell, 1969; Unger & Unger, 1952; Rogerson, 1935; and Peshkin, 1930). The study by Long, et al. (1958), was conducted to challenge the popular explanations, at that time, that the basis for the asthma is either allergic, as with continuous exposure to house dust, or emotional, specifically as interpersonal tension between the mother and the child with asthma. A third explanation being offered at that time was that the asthmatic symptoms were psychosomatic- a more complex explanation, combining environmental, emotional, and allergic factors as mutually responsible. The researchers concluded that house dust alone cannot be responsible for the production of asthma symptoms and

that children with asthma and their mothers have needs for closeness that are different from children without asthma. They also found that mothers of children with asthma wish to infantalize their children and that this way of relating to their children is based on their own psychological conflicts. While this study attempted to explore an interaction of physical and psychological explanations as responsible for asthmatic symptoms in children, the focus was on intrapsychic dynamics, rather than interactional, and tended to point the blame on the mother.

Another group of studies, particularly in the sixties, focused on the influence of faulty parental attitudes on childhood asthma. Rees (1963) used Kanner's (1957) criteria for classifying parental attitudes into satisfactory and unsatisfactory, and the unsatisfactory ones into overt rejection, perfectionism, and over-protection. He found a significantly higher incidence of unsatisfactory parental attitudes in the group of parents whose children had asthma than in a control group, with over-protection accounting for the frequent type of unsatisfactory parental attitudes in both groups. Rees looked into the mothers' histories to explain these attitudes and concluded that they were not the result of the asthma, but that they were predisposing factors, in

that they promote feelings in the child which precipitate the asthmatic symptoms. Again, the mother is blamed.

Pinkerton (1967) conducted a similar study, with similar conclusions. He linked over-protective parents with children with mild asthma, ambivalent parents with children with moderate asthma, and rejective parents with children with severe asthma. Pinkerton supported the use of temporary "parentectomy", along with psychotherapy, to treat these children.

Dubo, et al., (1961) attempted to demonstrate a relationship between family dynamics and the severity of childhood asthma, but they did not find one. Their methodology was questionable, however, as they used individual, rather than systemic, procedures to assess family function.

Purcell, et al., (1969) actually sent the family away from home for two weeks, leaving the child with a surrogate parent. Marked decrease in asthma symptoms in less than half the children, during the separation, were used to recommend the procedure for evaluation of the precipitating and perpetuating factors in a child's asthma. Peshkin (1975) referred the artificial separation of the child with asthma and the family as a "parentectomy", criticizing its subsequent use, for a period of time, as one of the treatments of choice for

children with severe asthma (Onnis, et al., 1986, p. 108). The family is viewed as a hindrance, instead of as a valuable support system.

In the late seventies, researchers began looking more seriously at the relationship between childhood asthma and families. Matus and Bush (1979) hypothesized that psychological adjustment, both individual and family, does contribute to the prediction of the frequency of asthma episodes in a severely affected group of patients. They compared the frequency of asthma episodes in the home with those in the hospital. Matus concluded that their results were consistent with a psychosomatic hypothesis, that psychological factors contribute significantly to the prediction of asthma episode frequency. They also found that family adjustment was a greater contributor than child adjustment in the prediction of asthma episodes in the home.

Lask and Matthew (1979) tested the effectiveness of one year of family therapy as an adjunct in the treatment program for asthma in 37 children. The goal in the family therapy sessions was to improve the coping skills of the families to handle the asthma episodes and to minimize stress related to the asthma. At the end of the year, positive psysiological changes found in the experimental group, but not in the control group were

less daily wheezing and lower total gas volume (less overinflation of the lungs). This study demonstrated that the family can have a positive influence on the child's asthma. This is the only report of a control study on family therapy as a treatment for asthma in children.

From the Philadelphia Child Guidance Center, Liebman, Minuchin, and Baker (1974) also report success in their trial of family therapy for seven children with asthma, but no control group was used for comparison. Also from the Philadelphia Center, Minuchin, Rosman, and Baker (1978) conducted a very influential study in the field of systemic family therapy to verify their clinical model for understanding "psychosomatic families". When asthmatic symptoms are triggered in response to emotional stimuli, rather than physiological ones, the child is said to have "psychosomatic asthma". These researchers compared three psychosomatic groups, including a psychosomatic asthma group, with two non-psychosomatic groups, on the Wiltwyck Family Task (Minuchin; Montalvo; Guerny; Rosman; Schumer; 1967). The significant findings were as follows: the psychosomatic groups demonstrated: (1) lower levels of interpersonal differentiation than the "normal" families; (2) a greater degree of overprotectiveness than the "normal" groups; (3) fixed alliance patterns, rather than flexibility and

creativity; and (4) diffusion, denial, or avoidance of conflict, whereas the "normal" families were able to both agree and disagree more readily. Psychosomatic asthma symptoms are understood by Minuchin's group as efforts to maintain these family transactional patterns. The researchers suggest not that family pathology is responsible for the asthma symptoms, but that a reciprocal cycle of mutual influence is in operation. The family task is an appropriately systemic method of collecting interactional data.

The four transactional patterns reported by the Philadelphia Group were also documented by Onnis, Tortolani, and Cancrini (1986), using the same family task. Neither group, however, demonstrated that they are, as Onnis, et al., state, "linked to the emergence and, above all, the perpetuation of the asthmatic condition" (p. 112).

Research on childhood asthma began with purely physiological factors, to individual psychological problems in the child and/or mother and father, to more relational factors. Until recently, systemic methods have not been used. As researchers have begun to explore the child's asthma in the context of her/his family relationships, it seems natural to expand this exploration to the next level of meaningful relation-

ships, the health care system in which she/he is being treated. The next section reviews some of the major issues in medical management.

Issues In Current Medical Management

The current medical understanding of childhood asthma is that it is a chronic metabolic disease involving the autonomic nervous system (Lewiston, 1986) and the respiratory system, characterized by varying degrees of central and peripheral airway obstruction (Hen, 1986, p. 92). The muscles around the bronchioles in the lungs tighten, narrowing the air passage. The cells lining the passage swell, narrowing the airway even more, and then secrete mucous, blocking the flow of air further. To the degree that breathing becomes so uncomfortable that it leads to a disruption in the child's usual daily activity, she/he is said to be having an asthma "attack" (Plaut, 1983, p. 37), or "episode". The precipitating factors to this process are explained as "triggers". Triggers to an episode in a person with asthma can be viral infections, inhaled pollutants, a change in weather, certain antigen-antibody reactions, exercise, certain medications, and emotional outburst (Hen, 1986; Plaut, 1983).

Asthma is commonly categorized into three levels of severity: mild episodic asthma, comprising seventy to

seventy-five percent of children with asthma; frequent episodic asthma, comprising twenty to twenty-five percent of children with asthma; and chronic severe asthma, comprising one to two percent of children with asthma. This classification is based on the number and severity of episodes per year, level of functional impairment, and the frequency of medication use (Pearlman, et al., 1980, p. 581). All three groups are treated with medication, either preventively or symptomatically. The mild group is often symptom-free, while the severe group experiences symptoms on a daily basis. About half of the mild group will go into long-term remission during adolescence, while the other half will continue to be symptomatic through early adulthood. "When asthma is 'severe' at 14 years of age, the chances of long-term remission are less than 5% (Hen, 1986, p. 96).

An alternative system of classification for asthma is: Intermittent, Chronic, and Indeterminant (not clearly either one) (Ekwo, Weinberger, & Miles, 1978). This is a simpler system of classification, relying only on the frequency of symptoms.

Another type of classification of asthma is whether or not the asthma is in good control (Ekwo, et al., 1978). The criteria are: (1) "no emergency physician visits" and (2) "absence of symptoms not promptly

relieved with the therapeutic measures" (Schwartz, 1984).

Recognized medical treatment goals in childhood asthma are outlined by Hen (1986, p. 93):

1. Maximum possible control of symptoms with a minimal number of the safest medications.
2. Participation in normal daily activities and sports without restrictions or with minimal and specific restrictions.
3. Prevention of acute episodes that require emergency treatment.
4. Reduction of the number and frequency of hospitalizations.
5. Education of the patient and family to understand, accept, and manage asthma within the context of the family's lifestyle.
6. Relief of airway obstruction and normalization of pulmonary function.
7. Improve the long-term prognosis.
8. Normal growth development.
9. Minimization of school absenteeism.

Aggressive medical treatment when children are young is believed to be the key to minimizing the severity and chronicity of their asthma as they grow older (Hen, 1986). More effective medications, new at-home medication delivery devices (nebulizers), new at-home assessment devices (peak-flow meters), new preventative medications, and a recent trend of Americans taking more responsibility for their health are all responsible for the manageability of asthma (Plaut, 1984, p. 10-11). In response to the problem of increased morbidity and mortality from asthma in spite of available medical care, several agencies, such at the National Institute of Health and the American Lung Association, have developed

asthma education programs with the goal of self-management education for patients and, in the case of children, their parents. There are currently at least eleven pediatric programs in the country (Rachelefsky, 1986). "Asthma education programs are based on social and behavioral theories stating that patients, traditionally passive, can be 'activated' to become participants, even full collaborators, in their health care, sharing this responsibility with their health care providers" (Hindi-Alexander, 1987, p. 492).

One such group self-management education program, and the only one New England has had (Plaut, 1988), is described by Plaut (1984) as it was practiced in his office until recently. The group was conducted by himself, and his partner physician. "The goald of the program were:

-to increase parents' knowledge of facts and myths about asthma, its treatment and the prevention of attacks.

-to provide a comfortable setting for sharing feelings about the ways in which asthma affects the child, parents and others.

-to build the family's skills in monitoring the child with asthma, recognizing the onset of 'attacks' and making appropriate decisions about

using medications, contacting practitioners, dealing with schools, friends, and babysitters"
(Plaut, 1984, p. 90).

Plaut's practice encouraged parents of "children with asthma" to participate in two four-hour training sessions. Children were taught to manage their asthma in the office, not in the education groups (Plaut, 1988). Parents in Plaut's group often then met together with their children for the remainder of the training session. Other practices conduct training sessions for children with asthma and their siblings in addition to the parent groups (Rachelefsky, 1986).

A review of asthma self-management programs (Rachelefsky, 1986) concludes they are an effective tool for the improvement of asthma in children and adults. Favorable results for children with asthma and their families include: decreased emergency room visits; decreased unscheduled doctor visits; improved school attendance; improved school performance; change in the health focus of control from health care professional to self/family; decreased anxiety for children about the asthma; increased self-management skills for children and/or their parents; and parents' perceptions of improved communication with their children's physicians. One study (Weiss, 1981) questioned parents about the degree of interruptions in their daily activities due to

their child's asthma, and found significant decrease after the education program. The results vary as do the research designs and the training programs, but the general trend is positive.

In conclusion, asthma for a child is a metabolic and respiratory disease that interferes with her/his normal daily activities and family life. When severe, asthma threatens the child's life. The disruption that occurs in order to care for the child's health can be tremendous, and can encourage over-dependence of the child and family on the health care provider. A discrepancy appears to exist between the recognized increased capacity of medicine to treat asthma as a manageable disease and the increase over the last ten years in the morbidity and mortality rates of asthma. Several myths about this disease are cited as interfering with effective treatment.

The current trend in thinking is to work toward a greater degree of a sharing of responsibility for the child's health among the child, the family, and the health care provider through education and self-management training, either in the health office or through group programs. Outcome studies on self-management education programs for families of children with asthma have claimed success in the areas of decreased morbidity and in the improvement of daily life.

Yet, they are not widely used; for example, the only formal program in New England is no longer in existence (Plaut, 1989). This observation has not yet been addressed in literature. The effectiveness of the less formal training that probably occurs in the office has not been studied. An important question to be asked is what is known about the relationship between the child, her/his caretaking parents, and the child's physician. How is conflict or disagreement related to outcome of the asthma?

A Critical Review of the Research on Conflict/Disagreement in The Relationship between the Child's Parent and The Child's Physician

A recent report (Pediatrics in Review, no author, 1988) in the pediatric literature summarized the common findings among clinicians and researchers on asthmatic children who have died from their illness (Kravis, et al., 1984; Williams, et al., 1975). The high-risk factors identified were: the ten to fourteen year-old age group; inappropriate use of medication inhalers; lack of physician awareness of the fatality of the disease; chronic wheezing since two years of age; physical complications; and psychosocial factors such as depression, denial of illness, or conflict between patient and caretakers. The review is brief, and

research methods are not included. The high-risk factors identified are associated with death, but not necessarily with control of the asthma on an ongoing basis.

A study on death in childhood asthma, not included in the review above, was reported by Strunk, Mrazek, Fuhrmann, and LaBreque (1985). Attempting to differentiate the characteristics of children who die from asthma from those who don't, Strunk, et al., matched two groups of twenty-one each for age and gender. Severity of illness was matched for only nine of the study subjects. The study group was composed of children who had died between the ages of eight and thirteen years. The control group were children who were alive, and usually had less severe forms of asthma. Neither group appears to have been selected at random. The hospital records for each of the asthmatic children, which included psychiatric evaluations of both patient and family adjustment to the chronic disease, were reviewed. A list of fifty-seven physiological and psychological variables were constructed, based on a review of the literature and on the researchers' clinical experience. The variables were coded by a pediatric allergist, a psychologist, and a child psychiatrist, independently, to help ensure reliability. A discriminant analysis was performed on the data, to differentiate the two groups.

The psychological and social variables that were found to be clearly characteristic of the asthmatic children who had died were as follows: disregard of asthmatic symptoms, inadequate hospital self-care, patient-staff conflict, parent-staff conflict, patient-parent conflict, manipulative use of asthma, emotional disturbance, depressive symptoms, history of emotional/behavioral reactions to separation or loss, and family dysfunction. Some of the findings of this study are supported by the 1988 review, above. Because this was the first study of its kind to use a control group, it is even more valuable. The further specification of psychological variables provides a greater understanding of the context for asthmatic symptomatology.

When discriminant analyses were performed on the fourteen distinguishing variables, four physical variables and four psychosocial variables were found to most consistently contribute to the prediction of death. Of interest here are the psychosocial contributors: disregard of asthmatic symptoms, deficient self-care in the hospital, patient-staff conflict, and depressive symptoms. Three of the four of these findings were directly related to the child's or family's relationship with the health care system. Disregard of asthmatic symptoms "was noted to be present if there was documentation that the child was aware of an asthma

attack but had been unwilling to share that knowledge with the staff" (p. 1196). Deficient self-care was noted when the child failed to learn age-appropriate self-care by the time of hospital discharge. Parent-staff conflict was noted when the parents ignored or refused medical advice or treatment, but the reverse direction of conflict was not described, and probably not explored. The definitions of the psychological variables are general and open to subjectivity. Although there were two independent coders, they were not blind to the subjects.

The discriminant analyses did show however, that the physiological variables made little contribution to the prediction of death from asthma without the addition of the psychological variables. The results of this study seem to support a contextual explanation for the chronic, severe and, in fact, life threatening nature to some cases of childhood asthma. Without the careful exploration of major influences in the child's life, including the significant relationships of family and health care professionals for chronically ill children, the physical factors would take on a false significance. This study cannot be regarded, however, as good systemic research. The description of the variables about conflict is linear, implying that all the responsibility, or even fault, lies with the patient and her/his parents.

A more systemic approach would have included the interactions between or among the involved persons.

An additional finding in the study of Strunk, et al., is noteworthy, as it has been reported elsewhere (Klinnert, et al., 1990; Pediatrics in Review, 1988). In reviewing the hospital records of those children who died from asthma, a significant number were adolescents. Strunk, et al., have speculated an interaction between the psychological issues and the adolescent developmental issues as fatal for these children (p. 1198). On the other hand, perhaps the physiological changes that occur in early adolescence can account for this finding.

The variables of conflict between child and physician, and conflict between parent and physician were again isolated in another study on children who died from asthma (Miller and Strunk, 1988). This study included twelve children ages ten through eighteen who died from their asthma and twelve controls, similar in age, gender, and severity of the asthma, and steroid use. The controls had survived an episode that was considered to have been life-threatening within the previous three years. Although the number of subjects in this study was smaller than in the former, the criteria for the selection of the control group was much more stringent, although still not at random.

Three categories of variables were tested for significance: physiologic, psychologic (including parent-child conflict, parent-physician conflict, and child-physicican conflict), and quality of asthma care. Conflict was reported as present by parent and/or physician and "defined as an ongoing problematic relationship engendering emotional discord consisting of disagreement, frustration, and dissatisfaction" (Strunk & Miller, 1989, p. 1296). The conflict also had to have been present for six months preceding the identified episode. Fisher's Exact Test (a 2x2 contingency table; p. 1297) was used to analyze the data from the conflict variables. Other variables were studied independently.

This time, conflict did not significantly differentiate the study group from the control of patients. No explanation is obvious for the discrepancy in this finding between the two studies by Strunk, and the authors have not commented on it. The operational definitions for conflict differ, the latter definition being a broader and more loosely defined one, yet covering a greater period of time. Another important difference between the studies is the age range of the patients, the latter study focusing more narrowly on adolescence. It may be that conflict between family and physician is not as critical a factor when the child is an adolescent as when she/he is a younger child.

A multiple regression analysis might have been useful in selecting which variables when grouped together differentiated between groups.

Onnis, Tortolani, and Cancrini (1986) researched chronically factors in childhood asthma. Part of their research addressed a particular relationship between the child's asthma and the larger health care system. The researchers hypothesized that the type of health care families request for their children's asthma - usually medical-pharmacological - is determined by the service usually offered by the health care system, rather than by their own perceptions of what influences the asthma. One hundred young walk-in patients, apparently picked consecutively, who were coming to this clinic for the first time, infants through age twelve, and accompanying family members were interviewed at a university pediatric clinic to learn the following: (1) type of treatment used for the first asthmatic attack; (2) treatment used in subsequent attacks; (3) family's perception of factors influencing the asthma; (4) doctors' perceptions of influencing factors; (5) type of request and expectations of the family regarding the service and their attitudes toward the treatment; (6) willingness of the family to try a different kind of treatment.

In all one hundred cases, the intervention used for the asthma was medical-pharmalogical. Onnis, et al.,

identified this as an influence in the course of the illness that shaped subsequent behavior. The families learned to continue this type of treatment both independently, and with physician consultation, for recurring attacks. The researchers also learned, that the families were not only aware that asthma can be influenced by emotional factors, but thirty percent of them believed that emotional factors usually contributed to and helped to precipitate the illness. Only 3.9 percent of physicians interviewed believed emotional influences had contributed to the attacks. Onnis, et al., concluded, "'the quality of the demand' remains confined to its most limited expression by a response that continues to be oriented to a strictly medical-pharmacological appoach" (p. 111).

Although sixty percent of the patients had not improved from the medical approach, this approach was continued. Ninety-seven percent of these patients were referred to an allergist. The researchers found that forty-eight percent of the patients and families demonstrated "a sense of passivity or weariness with regard to the intervention itself or often (viewed) the medical approach being used with skepticism because of the lack of any specific results" (p. 111). At the same time, Onnis, et al., found this same number of families quite willing to try a new approach. The researchers

offered a program that would combine self-management skill training with an exploration of the emotionally contributing factors to the illness. There is no account of this new plan of intervention, however.

This is an example of an exploratory study that has outlined a sequence of interactions between parents of asthmatic children and their health care providers in an every day management situation. The reciprocal nature of the patient-family-health care providers' transactions is illuminated by the parents' willingness to continue to try and solve the problem of the illness in the way it has been punctuated by the health care system, even when it wasn't working, and when their own perceptions were that the negative influences on the asthma were partially emotional. The explanation offered by Onnis, et al., is that the families were in a position of less power than the professionals. While the result of the new plan is not available, the parents' enthusiasm to participate, rather than the passivity showed with the former treatment, is promising. It seems it would be important to recognize the families' position of power constructively in the treatment plan. Just as the self-management skills are imparted for the medical response to asthmatic symptoms, families can be in charge of the emotional exploration as well, with the therapist as consultant.

While interview data provides a rich source of information not otherwise accessible, some problems are likely in the data analysis stage. In this study, whatever family members accompanied the child with asthma were interviewed. It is not stated, however, which and how many different family members were interviewed. The interviewee varied from case to case. While the researchers' intentions were to be systemic, too many uncontrolled variables have been introduced.

Specific methodology for this research is not available, other than sample selection. The population is from a clinic in Rome, limiting generalizability to that location. Findings are presented without an explanation of how the data was analyzed. Not all percentages are reported. The strength of the conclusions, then, are weakened.

In a case study report by Fialkov & Miller (1981) a parallel is described between the transactional patterns of psychosomatic families as outlined by Minuchin, et al. (1978), and the behavior of hospital staff in response to two patients with repeated hospitalizations for asthma. The four characteristics of enmeshment, overprotectiveness, rigidity, and avoidance of conflict resolution were observed in the staff, as well as a dysfunctional triangle with the child and family. The behaviors of all involved are explained as negatively reinforcing one

another toward a worsening of the child's condition, and for the first of the two children, death. In the case of the second child, the staff were given the opportunity to discuss the problems and to view his symptoms in a positive way. Restructuring of staff roles and tasks were undertaken, and this child's condition improved. Although the authors have attempted to apply structural theory to solve the problem, they unfortunately refer to the hospital environment at "psychosomatogenic" (p.793), thereby assigning linear causality and blame. Their point, however, is that the hospital is a powerful influence on the course of an illness. While this is a report of two cases only, and was probably written retrospectively, it seems to represent one of the few descriptions of child/family/health care provider system interaction related to asthma. Further exploratory of this nature is needed to begin to understand the dynamics of the relationships among the child/family/health care provider system. Even case studies need to account more thoroughly for their specific methodology used to collect and analyze the data.

Summary

In conclusion, systems researchers are just beginning to explore the relationship between the interactions among the patient/family/health care system

and childhood asthma. A recursive pattern has been described by experts in the medical-psychiatric field that associates an overdependence of parents on their children's physicians with the severe and chronic nature of their children's asthma. One empirical study that has included larger system variables, such as patient-hospital staff conflict and parent-staff conflict, have found them to be significant contributors in the prediction of death in children with asthma. A later empirical study came to the reverse conclusion. Studies in the literature on the child/family/physician relationship are too few. Further demonstrations of conflict in this system is needed, to draw any conclusions, but in only one instance does there seem to be anything close to a replication study.

The current direction of asthma education in the medical literature places responsibility for the improvement of the child's asthma to all the parts of the child/family/health care system. A study in a clinic in Rome found that the compliance of families of children with asthma to a medical treatment regime that does not include work with the emotional factors they perceive to be partially responsible for the asthmatic symptoms may be linked to the chronicity of some cases of childhood asthma.

It seems important, then, to include the ideas of families and health care providers, as partners in the process of treatment planning and intervention. What are their ideas about the treatment process? What do they see as problems and how do they think things might work better? Do family members and physicians agree with one another? To construct a balanced picture, the perspectives of both families and physicians would give us some information we don't yet have.

Are areas of disagreement related to how well the asthma is controlled? Too few studies have been conducted to say conclusively that disagreement or conflict in this system is a significantly contributing factor in the perpetuation of asthma symptoms in children. Statistical analysis is needed to investigate the relationship between disagreement and control of the child's asthma.

CHAPTER 3

RESEARCH DESIGN AND METHODOLOGY

Research Objective One

Determine the percentages of each type of Disagreement in the primary care parent - primary care physician pair for each of the nine Substantive Areas listed under Data Collections, below.

Research Objective Two: Hypothesis

Test the following hypothesis:

Ha: When a group of children aged one through twenty whose asthma is in control and a group of similarly-aged children whose asthma is not in control, are compared for presence of Disagreement in each primary care parent - primary care physician pair, the groups will differ, for each of the nine Substantive Areas, on at least one of the following measures: Observed Disagreement, Parent Perceived Disagreement, Physician Perceived Disagreement, Parent Inaccuracy of Perceptions, or Physician Inaccuracy of Perceptions.

Research Design and Methodology

This was an exploratory study, as so little research had been done on this problem. From the review of the

literature, the researcher constructed nine Substantive Areas (see Data Collection, below) of probable Disagreement in a parent-physician relationship. For the first goal of the study, these nine Substantive Areas were compared with one another for each type of Disagreement/Inaccuracy, if any, to determine which seemed most important.

For the second goal of the study, a causal-comparative design was used to test the hypothesis that Disagreement is a possible cause of uncontrolled asthma. Disagreement values in parent-physician pairs whose children's asthma was in control were compared with Disagreement values in parent-physician pairs whose children's asthma was not in control.

Definition of Terms

Primary care parent

The parent whose relationship with the child's physician will be studied; the parent who takes major responsibility for the care and/or supervision of care of the child's asthma; if both parents assume equal responsibility for this role, then either parent.

Disagreement

Significantly different responses between the questions being compared.

Observed Disagreement

Different responses to Type 1 and Type 2 questions (Types 1, 2, 3, and 4 questions described under Data Collection Instrument) are obtained when compared.

Parent Perceived Disagreement

Different responses to Type 1 and Type 2 questions are obtained when compared.

Physician Perceived Disagreement

Different responses to Type 3 and Type 4 questions are obtained when compared.

Parent Inaccuracy of Perceptions

Same responses to Type 2 and Type 3 questions are obtained when compared.

Physician Inaccuracy of Perceptions

Same responses are obtained to Type 1 and Type 4 questions when compared.

Control of the asthma was measured in two ways:

(1) Control (V) by the number of unscheduled visits to the physician's office (Edwo, Weinberger, and Miles, 1978), in the twelve months preceding the subject's participation in the study, and

(2) Control (H) by the number of hospitalizations in the previous year.

Variables

Disagreement

For each of the nine Substantive Areas, three types of Disagreement will be measured:

Observed Disagreement; Parent Perceived Disagreement, and Physician Perceived Disagreement, and two types of Inaccuracy of Perceptions: Parents Inaccuracy of Perceptions and Physician Inaccuracy of Perceptions.

Control

Control of the asthma will be measured as "in control" or "not in control" (see definition).

Population

Selection of The Subjects

Selection was done by soliciting volunteers.

Geographic Location

The medical practices were located in Turners Falls, Greenfield, and Holyoke. The practice in Holyoke had a large hispanic population; the others were mostly white.

Physicians

Twelve physicians, all white, participated in the study, including three women and nine men, one family practitioner and eleven pediatricians, aged thirty-six to fifty-seven. Years in practice ranged from two through twenty-seven. the percent of pediatric patients in their practices with asthma ranged from one through twenty percent. In thirty-nine percent of the cases, the physician knew the patient very well; in twenty-five percent of the cases, the physician knew the patient fairly well; and in fourteen percent of the cases, the physician did not know thepatient very well; in twenty-one percent of the cases, this information was missing. The number of patients per physician ranged from 1 to 11. Although the researcher originally intended to include only those physicians who had at least four parent participants, a computer analysis of outcome variables revealed no difference when the physicians with fewer parents were included in the study.

Primary Parents

Fifty-seven parents participated in the study, including fifty-six mothers and one father, aged twenty-one to forty-seven. Income levels ranged from below eleven thousand dollars a year to above forty-five thousand dollars a year.

Child with Asthma

Fifty-nine children participated in the study, including thirty-four boys and twenty-five girls, aged one through twenty years, all diagnosed with asthma at least one year prior to participation in the study.

Control of the Asthma

Parents reported forty-four children had not been hospitalized in the previous year, and fourteen had one or more hospitalization; fourteen children had no unscheduled visits to the physician's office, fourteen children had one to two unscheduled visits, and thirty-one children had three or more unscheduled visits in the previous year.

Data Collection Procedures

Physician Introductory Letters (see Appendix A) were sent to all pediatricians and family practitioners within the geographic location specified, A listing was obtained from the telephone books. The researcher briefly introduced the proposal for the study and requested a ten minute interview in person or by telephone with the physician to further explain her plan. A physician Consent Form was signed by the physicians if and when they agreed to participate (see Appendix B).

The researcher then requested permision to send Parent Questionnaires (see Appendix C) with Parent Introductory Letter/Consent Forms (see Appendix B) which introduced the study to all parents of all patients with asthma between the ages of one and twenty years, and who have been diagnosed with asthma at least one year prior to participation in the study. Only the parent who has primary responsibility for managing the asthma was asked to respond to the questionnaire; if both parents take equal responsibility, they were asked to choose one of them.

In one group practice, the physicians preferred to introduce the researcher in person to the parents. In this case, the researcher spent five days in the office, and was introduced to all willing parents of children with asthma who came in to the office. The researcher briefly introduced the study to each parent and then personally handed her/him the consent form and Parent Questionnaire to take home and decide whether to complete it.

Once a parent returned a completed questionnaire, with a signed consent form, the researcher then sent or gave a Physician Questionnaire to the appropriate physician.

To maximize subject participation, a reward was promised and sent to all participants upon return of the

completed questionnaire. The reward was their choice of two paperback books on asthma to which their child's doctor agreed: a recently published pocket version of a manual for parents on asthma in children by Thomas Plaut and a recently published book on asthma for children to read by Eileen Savage. The content of the books was unrelated to the intent of the study.

Data Collection Instrument

Questionnaires (Appendix C) to measure parents' perceptions of the asthma and physicians' perceptions of the asthma were designed by the researcher, and reviewed for clarity by her committee and for medical accuracy by a nationally recongized research consultant on the medical treatment of asthma in children. The categories, or Substantive Areas for the questions are based on both the revieww of the literature and the interview guides used by Keliinman (1978), and adapted by the researcher. The Substantive Area of Type of Relationship is based on the ideas of Parsons (Antonovsky, 1981; Cockerham, 1986). The nine substantive areas are: (1) Beliefs about causes of the condition of asthma; (2) Assessment of the triggers to the asthmatic symptoms; (3) Evaluation of approaches to treatment of the asthma; (4) Evaluation of qualitative measure of "good control" of the asthma; (5) Expectation of future course of the asthma; (6)

Evaluation of severity level of the asthma; (7) Evaluation of quantitative measures of "good control" of the asthma; (8) Assessment of type of relationship between parent and physician; (9) Satisfaction with the parent-physician relationship.

Kleinman (1980) stresses the importance of distinguishing between the ideas of the patient and those of the practitioner about the sickness and its treatment. each member of the system evaluates and assigns meaning to the episodes of illness. The transactions between these sets of ideas are the focus of this study.

The questionnaires include two subsets of nine questions, based on the nine substantive areas: one set for parents/physicians to answer about their own ideas, and one set for them to reflect how they think the other would respond. The total of 18 questions for the parents are essentially the same as those for the physicians, excepting some minor wording differences. The questions are asked in four different ways. Type 1 questions were posed to parents to elicit their own ideas about the child's asthma. For example, "Please rank order, from 1 to 5, what you consider to be the most likely reasons this child has asthma." Type 2 questions were posed to parents for their guesses about the physician's ideas about the asthma. For example, "Please rank order what you think your child's doctor believes to be the most

likely reasons your child has asthma." Type 3 questions were posed to physicians for their won ideas about the asthma and Type 4 questions were posed to physicians for their guesses about a particular parent's ideas about the asthma. They are arranged alternately, so that the odd numbered questions ask the subject about self, and the even numbered questions ask about other. See Table 1: Layout of Data.

Subjects are instructed to rank-order the response choices for the first ten questions, the first five Substantive Areas, and to give one answer only to questions 11 through 18, the last four Substantive Areas. For example, Question 1 reads,

"In your opinion, how likely are the following factors to "trigger" (bring on) asthmatic symptoms in this patient? Please rank order your responses from 1 to 6.
( ) A. Exercise
( ) B. Upper respiratory infection
( ) C. Pollutants
( ) D. Allergy
( ) E. Cold Air
( ) F. Emotions."

and a single choice question reads,

"The following question concerns the number of hospitalizations, emergency room visits, and/or unscheduled visits to the physician's office per year as indicators of whether or not the child's asthma is in 'good control'. How many of any combinations of these per year might this patient have for you to consider her/his asthma to be in 'good control'? (CHECK ONE)
( ) A. 0
( ) B. 1 - 2
( ) C. 3 or more."

The rank-ordered response style of questioning was used

to reflect the idea that there is no right or wrong

answer, only preferences. Not all the questions, however, lended themselves to rank-ordering.

The questionnaires were translated into Spanish for the Spanish-speaking subjects. Only a few were given out, in person by the researcher, and only one was returned.

Construction of The Variables

Five variables were constructed to measure five different types of Disagreement: Observed Disagreement, Parent Perceived Disagreement, Physician Perceived Disagreement, Parent Inaccuracy of Perception and Physician Inaccuracy of Perception (see Table 1).

Observed Disagreement was noted when there was a differnce between the responses (Type 1 for Parents and Type 3 for Physicians) in a parent-physician pair to any of the questions which asked about one's own ideas. Parent Perceived Disagreement was noted when a difference was found between a parent's responses about her/his own ideas (Type 1) and his/her guess about the physician's ideas (Type 2). Physician Perceived Disagreement was noted when a difference was found between a physician's response about her/his own ideas to a particular question (Type 3) and her/his guess about the corresponding parent's ideas (Type 4). Inaccuracy of Perception was constructed to isolate the areas in which a parent and or

physician could not accurately predict how the other would respond. Parent Inaccuracy of Perception was noted when a difference was found between a parent's prediction aobut the corresponding physician's response (Type 2) and the physician's actual response about her/his own ideas (Type 3). Physician Inaccuracy of Perception was noted when a difference was found between a physician's prediction of a parent's response (Type 1) and the corresponding parent's actual response about her/his own ideas (Type 4).

Preparation of The Variables for Data Analysis

Computation of the Kendall rank correlation coefficient

(Siegal, 1956).

The first five Substantive Areas required the subjects to rank-order the responses to the questions. For each of the first five Substantive Areas, and for each of the five types of Disagreement, a Kendall's tau was created as a measure of Disagreement (25 tau's) between parent and physician. Next, a dummy variable was constructed to indicate whether the tau was significant. If the tau was significant, the dummy variable was assigned a "1" to indicate Disagreement, and if the tau was not significant, the variable was assigned a "0", to indicate no Disagreement.

The p-value associated with a tau depends upon both the number of objects ranked and the number of ties (Sillito, 1950). In most instances, p-values of exactly 0.05 are not available. So, the significance test for the rankings of five objects uses a p-value of 0.12 and for rankings of six or eight objects a p-value of 0.14.

Computation of single response items.

The last four categories (Substantive Areas) of questions required choosing a single response, rather than rank ordering the responses. For each of the five types of Disagreement, for each of the last four categories of questions, a variable was assigned that was coded "1" if the response were not the same and "0" if the responses were the same. In other words, a "1" indicates Disagreement and a "0" indicates agreement.

For example (see Table 1), when a response to Parent Question 15 was compared with a response to Physician Question 15, a Disagreement variable was assigned. If the responses were not the same, a "1" was assigned for Disagreement, and Observed Disagreement was noted for the parent-physician pair.

by using the "dummy variable", the first and second groups of Substantive Areas then had a common unit of Disagreement.

Data Analysis

For each of the nine categories of the data collected, a simple frequency count was done to determine the number of pairs who disagreed (Observed Disagreements), subjects who perceived disagreement (Parent Perceived and Physician Perceived Disagreement), and subjects who inaccurately predicted the responses of the other partner (Parent Inaccuracy and Physician Inaccuracy).

For the first research objective, to identify which of the nine Substantive Areas for each of the five types of Disagreement were important, the first five Substantive Areas were considered separately from the last four Areas, as they were different kinds of data. In order to distinguish which percentages of Disagreement were significantly different from the others, pairwise comparisons were done.

For the second research objective, the hypothesis, the parent-physician pairs were divided into groups, according to whether or not the child's asthma was in control. This division into groups was done twice, in two different ways. The first division was into two groups - controlled and not controlled, according to the definition of "control by hospitalization". The second division was into three groups - controlled, not

controlled (1-2 visits), and not controlled (3 or more visits), according the definition of "control by visits".

A frequency count was done for all the dummy variables for Disagreement and converted to percentages. To determine whether the difference between the two groups was statistically meaningful, the proportions were compared. Analysis of Variance was used, rather than the t-test, as more than two groups were sometimes compared. (p) was set at 0.1, as this was a exploratory study.

When the two groups were found to be statistically different, either by control-hospitalization or by control-visit, the researcher accepted the alternative hypothesis for that Substantive Area or Type of Disagreement/Inaccuracy, and concluded that the variable of Disagreement, between the primary care parent and the physician of a child with asthma, is related to the variable of control of the child's asthma. When the difference was not found to be statistically meaningful, the researcher concluded that the variable of disagreement, between parent and physician of a child with asthma, is not related to the variable of good control of the child's asthma for that particular Substantive Area or type of Disagreement/Inaccuracy.

CHAPTER 4

DATA RESULTS

The data presentation is divided into two groups. Group One encompasses Areas 1 through 5, including Question 1 through 10; with rank-ordered responses. Group Two encompasses Areas 6 through 9, including Questions 11 through 18, with single choice responses.

The purpose of this study was bifold: (1) first, to explore nine possible areas of disagreement between parents and physicians of children with asthma; and (2) second, to test for a significant relationship between Disagreement and control of the child's asthma.

For each type of Disagreement/Inaccuracy, Areas 1 through 5 (Group One) were compared with one another and Areas 6 through 9 (Group Two) were compared with one another for significant differences in percentages of Disagreement. The areas that appear significantly large are presented and described below.

Disagreement values for each parent-physician pair, for each area/type of Disagreement were analyzed for significance in relationship to whether or not the particular child's asthma was in control. Each Substantive Area by Type of Disagreement/Inaccuracy found to be significant is presented and described below, (see also, Table 3) comparing the C Group, in which the

child's asthma was in control, and the NC Group, in which the child's asthma was not in control. In Group One, only the primary responses are presented, and do not always account for the difference between the C Group and the NC Group.

Group One: Areas 1 (Causes), 2 (Triggers), 3 (Treatment), 4 (Qualitative Measure of Control), 5 (Future).

Observed Disagreement (OBS) in Area 4 was significantly higher than the other four areas. There were no significantly large areas of Parent Perceived Disagreement, Physician Perceived Disagreement, or Parent Inaccuracy noted in these first five areas. Physician Inaccuracy 4 was significantly higher than in the other four areas.

Disagreement/Inaccuracy values that were found to be significantly related to control (measured by the number of Hospitalizations and/or Visits) of asthma in children are: Area 1, Observed (OBS 1), Parent Inaccuracy (PTAC 1), and Physician Inaccuracy (PHYAC 1); Area 2, Observed (OBS 2), and Physician Inaccuracy (PHYAC 2); and in Area 4, Observed (OBS 4) and Parent Inaccuracy (PTAC 4); none were significant in Areas 3 or 5.

Areas 1: Causes

Observed Disagreement (OBS 1) was found to be significantly related to control of a child's asthma when

control was measured by the number of Hospitalizations (H). Among children whose asthma was in control (C), the amount of Disagreement in the primary responses about causes in parent-physician pairs was 57.1%. Among children whose asthma was not in control (NC), Disagreement in the parent-physician pairs was 57.2%. In 28.6% of the parent-physician pairs in each group, the paent selected "physiological" as the primary cause of the child's asthma. In the NC Group, more parents (7.1%) selected "family problems" when the physician selected "physiological" than in the C Group (2.4%).

Parent Inaccuracy (PTAC 1) was found to be significantly related to control (H) of a child's asthma. Parents inaccurately predicted the physician's primary response in 52.4% of the C pairs and 57.2% of the NC pairs. 33.3% of C parents inaccurately predicted the physician would say "environmental irritants" as a primary response when the physician said "physiological". 28.6% of NC parents inaccurately predicted the physician would say "environmental irritants" when the physician said "physiological". More parents in the NC Group (7.1%) said "family problems" than in the C Group (2.4%).

Physician Inaccuracy (PHYAC 1) was found to be significantly related to control (H) of a child's asthma. C physicians inaccurately predicted the primary responses to corresponding parents in 55% of the pairs; NC

physicians inaccurately predicted the primary responses to Area 1 in 60% of the pairs. In 35% of the C pairs, the physician inaccurately predicted the parent would say "physiological". In 20% of the C pairs, the parent said "environmental" when the physician predicted "physiological", and in 15% of the C pairs, the parent said "other". In 10% of the C pairs, the parent said "physiological" when the physician predicted "environmental". In 53.3% of the NC pairs, the physician inaccurately predicted the parent would say "physiological". In 33.3% of all the NC pairs, the parent said "environmental" when the physicians predicted "physiological"; in 13.3% of the NC pairs, the parent said "other"; and in 6.7% of the NC pairs, the parent said "family". Overall, C Physicians predicted C parents would say "physiological" as their primary response more often than they did (66.7%: 46.5%), while NC physicians were even more inaccurate (85.7%: 28.6%). In addition, NC physicians were more inaccurate than C physicians in predicting parents' second choice as "environmental irritants" (C, 28.6%: 32.6%; NC, 14.3%: 42.6%).

Area 2: Triggers

Observed Disagreement (OBS 2) was found to be significantly related to control (H) of a child's asthma. Disagreement in the primary responses, about what

triggers the child's asthmatic symptoms, between parents and physicians in the C Group was 57.2%; and in the NC Group was 53.3%. In 16.7% of the C pairs, the parent selected "allergy" when the physician did not; in 14.3% of the C pairs, the physician selected "upper respiratory infection". In 13.3% of the NC pairs, the parent selected "upper respiratory infection" when the physician selected "allergy"; in another 13.3%, the reverse pattern was noted.

Physician Inaccuracy (PHYAC 2) was significantly related to control (H) of a child's asthma. In 55% of the C pairs, the physician inaccurately predicted the parent's primary response. In 33.3% of the NC pairs, the physician inaccurately predicted the parent's response. In 25% of the C pairs, the physician inaccurately predicted the parent's primary response would be "upper respiratory infection"; half of these parents chose "allergy" for their primary responses. In 26.8% of the NC pairs, the physician inaccurately predicted the parent's primary response would be "upper respiratory infection"; the parents' actual primary responses were evenly split between "exercise" and "cold air".

Area 4: Qualitative Measure of Control

Observed Disagreement 4 (OBS 4) was both a significantly large area of Observed Disagreement and

significantly related to control (H) of the child's asthma. OBS 4 was noted in 11.5% of all the responses of parent-physician pairs to the question about qualitative measures of control. In the C Group, 67.5% of the pairs disagreed about the best measure of control. In the NC Group, 83.3% of the pairs disagreed. In 27.5% of the C pairs, the physician's primary response was "interference with daily activities" when that of the parent was either "visits" or "peak flow". In 41.7% of the NC pairs, the largest place of Disagreement was noted when the physician's primary response was "interference with daily activities" and that of the parent was either "visits" (25%) or "hospitalization" (16.7%).

Parent Inaccuracy 4 (PTAC 4) was significantly related to control (H) of the child's asthma. 77.5% of C parents inaccurately predicted the corresponding physician's primary response; 75% of NC parents inaccurately predicted the corresponding physician's primary response. 50% of C parents inaccurately predicted the corresponding physician's primary response of "interference with daily activities" or "school absence"; the parent thought the physician would say "visits" (35.5%) or "peak flow" (22.5%). 58.4% of NC parents inaccurately predicted the same physician response with "visits" (25%) and "peak flow" (33.4%).

Physician Inaccuracy 4 (PHYAC 4) was a significantly large area of Physician Inaccuracy. In 15.4% of all the pairs, the physician inaccurately predicted the responses of the corresponding parent. In 71.1% of the pairs, the physician inaccurately predicted the primary responses of the parent. 38.4% of physicians predicted the parent would say "interference with daily activities" for a primary response, when the parent said something else. 30.8% of the time, the parent said "peak flow" for a primary response, when the physician did not predict this response. PHYAC 4 was not significantly related to control of the child's asthma.

Group Two: Areas 6 (Severity), 7 Quantitative Measure of Control), 8 (Type of Relationship), and 9 (Satisfaction with Relationship).

Observed Disagreement (OBS) in Areas 6, 7, and 8 were significantly higher than in Area 9. Parent Perceived Disagreement (PTPR) in Areas 7 was significantly higher than in Areas 6, 8, and 9. Physician Perceived Disagreement (PHYPR) in Area 9 was significantly higher than in Areas 6, 7, and 8. Parent Inaccuracy (PTAC) in Area 7 was significantly higher than in Area 9, but not than in Areas 6 and 8. Physician Inaccuracy (PHYAC) in Areas 7 and 8 were significantly higher than in Area 9, but were not significantly different from each other or from PHYAC 6.

Disagreement/Inaccuracy values that were found to be significantly related to control of asthma in children are: in Area 6, Physician Perceived (PHYPR 6), Parent Inaccuracy (PTAC 6), and Physician Inaccuracy (PHYAC 6); in Area 7, Parent Inaccuracy (PTAC 7); in Area 8, Parent Perception (PTPR 8) and Physician Perception (PHYPR 8); and in Area 9, Observed (OBS 9) and Parent Inaccuracy (PTAC 9).

Area 6: Severity

Observed Disagreement 6 (OBS 6) was noted in 42% of the responses of parent/physician pairs and was a significantly large area of Observed Disagreement. In 26% of the pairs, the parent said the child's asthma was more severe than the child's physician said it was. For 15.8% of the pairs, the parent said the asthma was less severe than did the physician. OBS 6 was not significantly related to control of the asthma.

Physician Perceived Disagreement 6 (PHYPR 6) was significantly related to control of the child's asthma when control was measured by number of visits (V). In the C Group, 7.1% of physicians perceived Disagreement with the corresponding parent about severity of the child's asthma; in the NC Group with 3 or more visits, 27.5% of the physicians perceived Disagreement. 7.1% of C physicians thought the parent would say the asthma was

less severe than the physician did. 17.2% of NC physicians thought the parent would say the asthma was more severe than the physician did; 10.3% of NC physicians thought the parent would say the child's was less severe than the physician did.

Parent Inaccuracy 6 (PTAC 6) was significantly related to control of the asthma, when control was measured by unscheduled visits (V). In the C Group, 42.9% of parents inaccurately predicted the responses of the child's physician to the severity question; in the NC Group with 1-2 unscheduled visits, 15.4% of parents inaccurately predicted the physician's response; and in the NC Group with 3 or more unscheduled visits, 33.4% of parents inaccurately predicted the physician's response. In 28.5% of C pairs, the parent predicted that the child's physician would say that the asthma was more severe than the physician actually did say, while in 14.3% of C pairs, the parent predicted the physician would say the asthma was less severe than she/he did say. In the NC Group with 1-2 unscheduled visits, 7.7% of the parents predicted that the physician would say the asthma was more severe than she/he did say, while the other 7.7% predicted the physicians would say it was less severe. In the NC Group with 3 or more unscheduled visits, 13.3% of the parents predicted the physician would say the

asthma was more severe than she/he did say, while 20% inaccurately predicted the physician would say it was less severe.

Area 7: Quantitative Measure of Control

Observed Disagreement 7 (OBS 7) was a significantly large area of Observed Disagreement. 52.7% of the parent-physician pairs disagreed about how many hospitalizations, emergency room visits, and/or unscheduled visits to the doctor's office constitute "good" control of the child's asthma. In 29.8% of the pairs, parents were more stringent about their responses than corresponding physicians, while in 22.8% of the pairs, physicians were more stringent. OBS7 was not significantly related to control of the asthma.

Parent Perceived Disagreement 7 was a significantly large area of Parent Perceived Disagreement. In 32.2% of all the pairs, the parent perceived disagreement between her/his self and the physician about this measure of control. In 18.6% of parent-physician pairs, the parent thought her/his child's physician was more stringent about this measure than the parent was. In 13.6% of the pairs, the parent thought she/he was more stringent than the physician. PTPR 7 was not significantly related to control of the asthma.

Parent Inaccuracy 7 (PTAC 7) was both a significantly large area of Parent Inaccuracy and was significantly related to control (H) of the child's asthma. PTAC7 accounted for 42% of all the pairs. 28.6% of C Group parents versus 80% of NC Group parents incaccurately predicted the physician's response. In 7.2% of the C Group, the parent thought the physician was less stringent than the physician declared; in 21.5% of the C Group, the parent thought the physician was more stringent than thephysician declared. In the 32.4% of the NC Group, the parent thought the physician was less stringent than the physician declared; in 46.7% of the NC Group, the parent thought the physician was more stringent than the physician declared.

Physician Inaccuracy 7 (PHYAC 7) was a significantly large area Physician Inaccuracy. 47.3% of physicians inaccurately predicted the responses of corresponding parents to this question. 26.3% of physicians inaccurately predicted the parent's response would be less stringent than it was, while 21.1% inaccurately predicted it would be more stringent. PHYAC7 was not significantly related to control of the child's asthma.

Area 8: Type of Relationship

Observed Disagreement 8 (OBS 8) was noted in 46.6% of the parent-physician pairs, and was a significantly large

area of Observed Disagreement. In 12.5% of the pairs, the parent said she/he and the child's physician work together to manage the child's asthma, while that same physician said the physician makes most of the decisions. In 8.9% of the pairs, the parent said parent and physician work together, while that physician said the parent makes most of the decisions. In 10.7% of the pairs, the physician said parent and physician work together, while that same parent said the physician makes most of the decisions. In 12.5% of the pairs, the physician said parent and physician work together, while that parent said she/he as parent makes most of the decisions. OBS 8 was not significantly related to control of the asthma.

Parent Perception 8 (PTPR 8) was significantly related to control (V) of the child's asthma. None of the parents in the C Group perceived disagreement with the physician about the type of relationship they have. In the NC Group with 1-2 visits, 21.4% of parents perceived disagreement with the physician. In 14.3% of the pairs in this NC Group, the parent said the physician made most of the treatment decisions, while she/he thought the physician would say the parent and physician work together. In 7.1% of the pairs, the parent said she/he made most of the decisions, while she/he thought the physician would say they work together.

Physician Perception 8 (PHYPR 8) was significantly related to control (V) of the asthma. None of the physicians in the C Group perceived disagreement with the parent about the type of relationship they have, while 19.9% of physicians in the NC Group with 3 or more visits perceived disagreement with the parent. 10% of physicians in this NC Group thought the parent would say they work together when the physician did not agree; in this case, the physician was twice as likely to say the physician makes most of the decisions as to say the parent does. 6.6% of the NC physicians said they work together with the parent but thought the parent would not agree; in this case, other possible perceptions of parent responses were evenly split. 3.3% of NC physicians said the parent was more in charge, but thought the parent would disagree by saying the physician was.

Physician inaccuracy 8 (PHYAC 8) was a significantly large area of Physician Inaccuracy. In 44.6% of the pairs, the physician inaccurately predicted the response of the corresponding parent. In 23.2% of the pairs, the physician inaccurately predicted the parent would say they worked together, when the parent did not; in this case the parent was 116% more likely to say the parent makes more of the decisions than the physician does. In 21.4% of the pairs, the parent said they work together, when the physician predicted the parent would not; in

this case the physician was 140% more likely to say the physician makes more of the decisions than the parent does. PHYAC 8 was not significantly related to control of the child's asthma.

Area 9: Satisfaction with Relationships

Observed Disagreement 9 (OBS 9) was significantly related to control both by Hospitalization (H) and by Visit (V) of the child's asthma.

OBS 9 (H) In 16.7% of the C(H) Group, parent-physician pairs disagreed about their satisfaction with the relationship, while in 40% of the NC(H) Group, parent-physician pairs disagreed. In 12% of the C(H) pairs, the parent was satisfied with the relationship as it is, while the physician was not; in this case, the physician was nearly one and one-half times as likely to say she/he preferred the physician to become more involved than to say she/he preferred the parent to beome more involved. In 26.7% of the NC(H) pairs, the parent was satisfied while the physician was not. In this case, the physician was nearly three times as likely to say she/he preferred the parent to become more involved than to say she/he preferred the physician.

OBS 9 (V) In the C(V) Group, 0% of parent-physician pairs disagreed, while 15.4% of the pairs in the NC Group with 1-2 visits disagreed, and 47.7% of the pairs in the

NC Group with 3 or more visits disagreed. The disagreement in the NC(1-2) Group was evenly split between parent wanting the physician more involved and the physician wanting the parent more involved. In the NC(3+) Group, the results were almost identical to the NC(H) Group. In 26.7% of the pairs, the parent was satisfied when the physician was not, while in 6.7% of the pairs, the physician was satisfied when the parent was not. In 20% of the pairs, the physician wanted the parent to be more involved when the parent disagreed. Three-quarters of these parents were satisfied.

Physician Perception 9 (PHYPR 9) was a significantly large area of Physician Perception. In 33.3% of the pairs, the physician perceived disagreement with the parent. In 14.1% of the pairs, the physician was satisfied with the relationship and perceived that the parent was not satisfied. 12 out of 14 of these physicians thought the parent wanted the physician more involved. In 14.1% of the pairs, the physician was not satisfied and perceived that the parent was satisfied. 9 out of 14 of these physicians wanted the physician to be more involved. PHYPR 9 was not significantly related to control of the child's asthma.

Parent Inaccuracy 9 (PTAC 9) was significantly related to control (V) of the child's asthma. The percentage of Inaccuracy among the parent group whose

children's asthma was in control, was 7.1%; in the NC Group with 1-2 visits, 15.4%; and in the NC Group with 3 or more visits, 36.7%. When the 7.1% of C parents inaccurately predicted the physician was satisfied, the physician actually wanted the parent to be more involved. In the NC Group with 1-2 visits, 7.7% of the parents inaccurately thought the physician was satisfied when the physician actually wanted to be more involved and 7.7% of the parents inaccurately predicted the physician wanted the parent more involved when the physician was satisfied. In the NC Group with 3 or more visits, 30% of the parents inaccurately predicted the physician was satisfied; one-third of these physicians actually wanted to be more involved; two-thirds of these physicians actually wanted the parent to be more involved.

Data Summary

Major Areas of Disagreement/Inaccuracy, Group One

Area 4: Qualitative Measures of Control. Area 4 was a major area of Observed Disagreement and of Parent Inaccuracy. Disagreement was most often Observed in a parent-physician pair when the physician chose "interference with daily activities" and the parent chose "visits", "peak flow", or "number of hospitalizations" for the primary response to "best measure of control". The majority of inaccurate physicians predicted the

parent would choose "interference with daily activities" when the parent chose "peak flow".

Major Areas of Disagreement/Inaccuracy, Group Two

Area 6: Severity. Area 6 was a major area of Observed Disagreement in Group Two. The majority of Disagreement was Observed when the parent declared the child's asthma was more severe than the physician did.

Area 7: Quantitative Measure of Control. Area 7 was a major area of Observed Disagreement, of Parent Perceived Disagreement, of Parent Inaccuracy, and of Physician Inaccuracy. Disagreement was most often Observed in a parent and physician pair when the parent was more stringent on this measure than the physician. Of the parents who perceived Disagreement, more parents perceived the physician was more stringent than the parent. The majority of inaccurate parents predicted the physician was more stringent than the physician declared. The majority of inaccurate physicians predicted the parent's response as less stringent the parent declared.

Area 8: Type of Relationship. Area 8 was a major area of Observed Disagreement and Physician Inaccuracy. The majority of Disagreement in Area 8 was Observed when either parent or physician said they work together and the other said she/he makes most of the decisions. When physicians were inaccurate, in Area 8,

more of them predicted the parent would say they work together, when the parent said the parent makes most of the decisions.

Area 9: Satisfaction with Relationship. Area 9 was a major area of Physician Perceived Disagreement. The majority of physicians who were not satisfied with the relationship with a parent wanted to become more involved and thought the parent was satisfied.

Areas of Disagreement/Inaccuracy Significantly Related to Control of The Asthma

Area 1: Causes. Observed Disagreement (H), Parent Inaccuracy (H), and Physician Inaccuracy (H) in Area 1 were significantly related to control of the child's asthma. The same amount of primary Disagreement between parent and physician was noted in both the C and the NC Groups. Parents and physicians werre slightly more inaccurate in their predictions of primary responses in the NC Group than in the C Group. The most frequent content of the Disagreement/Inaccuracy about primary responses in this Area 1 was, for the parent, "environmental irritants" and for the physician, "physiological". What seemed to distinguish the C Group from the NC Group was that the parent was more likely in the NC Group than in the C Group to select "family problems" as a primary response, and inaccurately predicted the physician would select the same, when the

physician selected "phsiological". At the same time, the physician was more likely in the NC Group than in the C Group to inaccurately predict the parent would say "physiological".

Area 2: Triggers. Observed Disagreement (H) and Physician Inaccuracy (H) in Area 2 were significantly related to control of the child's asthma. The percentages of each in the primary responses were greater in the C Group than in the NC Group. The most frequent content of the primary response Disagreement/Inaccuracy in Area 2 was, for the C parent, "allergy" and, for the C physician, "upper respiratory infection". For NC pairs this pattern was noted as often as the reverse. The physicians inaccurately predicted "upper respiratory infection" when the C parent selected "allergy" and when the NC parent selected "exercise" or "cold air".

Area 4: Qualitative Measure of Control. Observed Disagreement (H) and Parent Inaccuracy (H) were significantly related to control of the child's asthma. Disagreement in primary responses of parent and physician were greater in the NC Group than in the C Group. The parents were slightly more inaccurate in predicting the physicians primary responses in the C Group than in the NC Group. The most frequent content of the primary response Disagreement was, for the C parent, "visits" or "peak flow", for the NC parent, "visits" or

"hospitalization"; for the C and NC physician, "interference with daily activities". The inaccurate C parent was more likely to predict "visits" and the NC parent to predict "peak flow".

Group Two

Area 6: Severity. Physician Perception (V) and Parent Inaccuracy (V) were significantly related to control of the child's asthma. Four times as many physicians in the NC Group as in the C Group perceived Disagreement, about the response to Area 6, with the corresponding parent. C physicians thought the parent would disagree by saying the asthma was less severe than the physician said it was; NC physicians thought the reverse. More parents in the C Group inaccurately predicted the physician's response than in the NC Group. C parents predicted the physician response as more severe than their own and NC parents predicted the physician response as less severe than their own.

Area 7: Quantitative Measure of Control. Parent Inaccuracy (H) in Area 7 was significantly related to control of the child's asthma. PTAC 7 was almost three times greater in the NC Group than in the C Group. In both groups, the parent predicted the physician was more stringent than the physician declared.

Area 8: Type of Relationship. Parent Perceived (V) and Physician Perceived (V) Disagreement were

significantly related to control of the child's asthma. There was no Disagreement perceived either by parents or by physicians in the C Groups. Both the NC parent and the NC physician, who perceived Disagreement, thought the physician maked more of the treatment decisions, and both thought the other would say they work together.

Area 9: Satisfaction with Relationship.

Observed Disagreement (H&V) and Parent Inaccuracy (V) were significantly related to control of the child's asthma. Disagreement in parent-physician pairs was greater in the NC Groups (H&V) than in the C Groups (H&V). The content of the Disagreement was similar, whether control was measured by (H) or by (V). There was no Disagreement between parents and physicians in the C(V) Group; in the C(H) Group, the parent was satisfied and the physician wanted to be more involved. In both the NC(H) Group and in the NC(V3+) Group, the physician wanted the parent to more involved. When C(V) and NC(V3+) parents inaccurately predicted the physician was satisfied, the physicians wanted the parent to be more involved.

CHAPTER 5

DISCUSSION

The Questionnaire

The questionnaires were constructed to investigate the interaction of ideas between parents and physicians of children with asthma. Subjective measures (Perceived Disagreement) as wee as relatively objective measures (Observed Disagreement), although considered separately, were equally weighted in the process off analyzing the results. The Parent and Physician Inaccuracy measures were constructed to attempt to have a reality check on the parents' and physicians' predictions of each other's responses, and happen to combine both the "subjective" and the "objective" qualities of each of the other measures. This interactive nature of the questionnaire distinguishes this study from those in the literature. Only Onnis, et al., have directly asked the parents of children with asthma for their ideas about the process of treatment, but they used an interview process, which is more difficult to analyze. Other researchers have attempted to collect only countable data, but have neglected to tap the valuable resource of the parents and/or child themselves.

The content of the questions was intended to reflect the meaning of the asthma and its management for each of the parent- physician pair. It was assumed at the beginning of the study that meaning, behavior and relationships are mutually influential.

Discussion of the Results

Objective One: Areas of Disagreement

Disagreement, in general, was very low in the first five Substantive Areas. The only values above ten percent were noted in Observed Disagreement in Qualitative Measures of Control and Physician Inaccuracy for Qualitative Measures of Control. On the other hand, Disagreement in the second four Substantive Areas was comparatively high. One reason for this discrepancy was probably the difference in the style of questions. As discussed under Data Analysis, the rank-ordered response questions allowed more room for slight disagreement, while the single-response questions, even when the similar responses were grouped together, allowed more room for disagreement. Another reason may have been the content of the questions themselves. One finding to support this explanation is that questions about "control" of the asthma was asked in both sections of the questionnaire, and yielded a comparatively high Disagreement value in both sections, although less in the

first. Areas 4, 6, 7, 8, and 9, then, may actually be more common areas of Disagreement than Areas 1, 2, 3, and 5.

Since no one else has studied these areas of Disagreement between parents of children with asthma and the physicians, there is no source of comparison. In Kleinman's (1980) extensive work with patient-practitioner transactions in treating illness in general, he found causes, treatment and severity to be important sources of conflict. Of these three areas, this study on childhood asthma supports only the severity issue as a source of disagreement.

Objective Two, The Hypothesis: The Relationship Between Disagreement and Control of The Asthma

The results support the hypothesis for Substantive Areas 1, 2, 4, 6, 7, 8, and 9 (Causes, Triggers, Qualitative Measures of Control, Level of Severity, Quantitative Measure of Control, Type of Relationship, and Satisfaction with Relationship). The results do not support the hypothesis for Substantive Areas 3 and 5 (Approaches to Treatment and Expectations of Future Course). The results also support the findings of previous studies reported in the literature, that disagreement or conflict between parents of the child with asthma and the child's physician is related to

control of the asthma. The results also support the findings of Onnis, et al., that the child's asthma is related to the context of the larger system in which it is being treated - the health care system. The question remains of direction of causality. Is the variable of Control of the asthma in itself responsible for the variable of Disagreement? Or is the Disagreement responsible for the asthma being "out of control"? This researcher suggests that the ideas of the child, the parents and the treating physician, and management of the asthma are mutually influential.

Areas of High Disagreement

Area 4: Qualitative Measures of Control. It is not surprising that the issue of defining and measuring control of the asthma is a significant source of Disagreement for parents and physicians. Control of the asthma is the problem focus of this study, as it is so difficult to maintain for some parents and their children with asthma. It is interesting that when the pairs disagreed, the physician's preferred response was "interference with daily activities" for the child and family, while the parent's preferred responses were "peak flow", using a special meter to measure the child's air flow, and "unscheduled visits to the office". The physician's response seems to reflect an interest in the

child's home environment, while the parent's response is focused on the medical environment. Perhaps both are reaching out to attempt to understand and appreciate the other's world. On the other hand, based on the medical literature on current treatment of childhood asthma, the content of the physician's preferred response is surprising. The researcher expected the physician to favor "peak flow" as the preferred method for a parent to evaluate a child's symptoms. One of the hypothesized reasons in the literature for the difficulty maintaining "good control" of asthma is that not all physicians may have updated knowledge on asthma care and prevention. Plaut (1991) found that the training of pediatric physicians and nurses at two New England health maintainance organizations in the most recent advances in asthma care, including the use of peak flow meters to monitor symptoms, resulted in a greater than two-thirds decrease in the number of hospital days for asthma in the HMO pediatric patients, indicating the utility of education in asthma care for medical professionals.

Area 6: Severity Level of The Asthma. This variable was measured by the perceived amount of interference with daily activities in the life of the child and family. It is not surprising that parents may often think this interference is more frequent than the

physician, because the parent lives with it everyday, and therefore knows more.

Area 7: Quantitative Measure of Control of The Asthma. It is also not surprising that the parent is more often more stringent than the physician, about the asthma, since unscheduled visits to the physician's office and/or hospitalizations are much more out of the normal range of behaviors for a family than for the professional role of the physician.

Area 8: Type of Parent-Physician Relationships.

This area yielded a high proportion of Disagreement. Half of all the subjects disagreed about whether the parent and physician work together or alone. When the parent said "together", the physician said either "physician alone" or "parent alone". When the physician said "together", the parent said either "parent alone" or "physician alone". Michael Glenn (1985) discusses the importance of a joint contract between patients and their physicians to maximize the benefits of the health care process. The literature on managing asthma in children stresses the importance of a partnership approach between the doctor and the parents. This cannot work if both partners don't see it the same way.

Areas of Disagreement Related to Control of The Asthma

Area 1: Causes. The only difference between the controlled asthma group and the uncontrolled asthma apparent from looking at the primary responses is the response of "family problems". This proportion is so small, however, that the difference may actually be in the secondary responses, which are of less importance.

Area 2: Triggers. Disagreement about triggers to the asthmatic symptoms was actually less in the uncontrolled asthma group than in the controlled group. One possible explanation is that the physician did not know as well the parents of the child whose asthma in control as the ones whose child was hospitalized.

Area 4: Qualitative Measure of Control. It is not surprising that a parent whose child was hospitalized would think of hospitalization as the primary measure of control of the asthma. However, this is probably a less useful measure, since it does little, in itself, to prevent the need for hospitalization.

Area 6: Severity Level of The Asthma. The more often the parent brought the child into the physician's office for unscheduled visits, the more often the physician perceived Disagreement with the parent about severity and the more often the parent was mistaken about the physician's assessment of the severity level. Of the physicians who thought the parent considered the asthma

to be more severe than the physician thought, the physician may have thought the parent was over-reacting. Of the physicians who thought the parents considered the asthma as less severe, the physician may have thought the parent and/or child was not doing enough at home to maintain the symptoms.

Area 7: Quantitative Measure of Control. The parent whose child had been hospitalized was much more likely than other parents to not know how the physician stood on this important issue. One might question whether, if the parent knew the physician considered any unscheduled visits to the physician or emergency room or any hospitalization in the last year to be a sign of unnecessarily out of control asthma, would the parent and/or child be more careful about the treatment at home? On the other hand, when the physician was less stringent than the parent, how did that influence home compliance with the treatment regime?

Area 8: Type of Relationship. This was a particularly impressive finding, because of the extreme difference in proportions between the C group and the NC group. None of the parents and physicians of children whose asthma was in control thought there was any Disagreement between them about the type of relationship they had, while parents and physicians of children whose asthma was not in control (by visits) did think they

disagreed about this. Actually, parents and physicians did disagree, in both the C Group and the NC Group, on whether they work together or only one is incharge, but they were aware of it only when extra office visits were necessary. The Parent Perceived Disagreement when only 1 or 2 visits were unscheduled, while the physician didn't perceive Disagreement, as a rule, until 3 or more visits were unscheduled. Again, the disruption for the physician, for whom it is the norm to be in the office, is less than for the parent, who probably has to change the family's usual schedule to get there. These extra office visits, while considered to be a sign that the asthma is not in control, may serve to increase awareness of one another's views.

The parent who perceives Disagreement with the child's physician may be scheduling extra visits because she/he perceives it is the physician who is in charge, and that only the physician can solve the problem. Both parents and physicians who believe the physician makes more ofthe decisions but thought the other would say they work together, may have the idea that they should, or at least, that the other thinks they should, be working together.

Antonovsky (1979) stresses the need for patients to have a sense of "coherence" in the world of health care, a sense that the medical behaviors make sense.

Antonovsky (1979) warns that, although the "democratic" style, shared decision-making, of physician patient relationship would seem to give the patient the best sense of coherence, it is not realistic, for two reasons. First, Antonovsky believes, such a close relationship may interfere with the physician's "neutrality". Second, he continues, such level of involvement cannot be expected of a patient who is in a dependent position and may be highly influenced by anxiety.

Parsons (Antonovsky, 1979) suggests that the "collegial" style of doctor-patient relationship is the most pragmatic in American health care. In the collegial style, the doctor is the expert and does not share the decision-making process with the patient. The Review of The Literature for this study reflects a different stand on the issue of type or relationship. Most medical experts agree that parents, children, and physicians must share the task of making decisions.

This researcher also differs with Parsons and Antonovsky. Compliance cannot be expected in the traditional, authoritarian sense. A sense of involvement and responsibility can facilitate a more active stance. On the other hand, with a life threatening condition as asthma can sometimes be, the physician has a responsibility to convey the seriousness of the asthma to the child and parents. Perhaps, also, there is a

difference with parents of pediatric patients. Parents may have a greater capacity for the emotional distance necessary that the patient may not. Parents may also have a greater level of motivation to take care of the child than the child has, yet, for her or himself.

Area 9: Satisfaction with The Parent - Physician Relationship. Parents of young patients with asthma, who need to manage the child's at home, need to have a sense of self-efficacy, that what they're doing is working. They need a sense of control. When a parent believes she/he is doing everything possible to take care of the child, and yet the child's asthma brings her/him into the hospital, the parent's sense of coherence, sense of self-efficacy, and sense of control are threatened. The parent then has to hgive up most of her/his control over to the hospital and the physician. Cockerham (1986, p. 141) points out that the patient and family have much more influence over the doctor-patient relationship when the patient is at home, rather than at the hospital, where institutional policies have more power. This idea may help explain why parents and physicians disagree more over satisfaction with the relationship with one another when the child has been recently hospitalized. Even though the child has returned home, the parent may be

continue to be influenced by the organization of the hospital. She/he may feel disempowered, and less effective.

Disatisfaction in one of the pair usually meant wanting the other person to become more involved. When the child had been recently hospitalized, it was usually the physician who wnated the parent more involved. When only 1 or 2 visits were unscheduled, the group was more evenly split, but when 3 or more visits were unscheduled, the physician again wanted the parent more involved. The extreme situation is likely to make anyone feel more alone and wanting help. It may take the extreme situation to ask for a change in the definition of a relationship.

Conclusions

"Good control" of the child's asthma, including how to control the symptoms, how to monitor the symptoms, and how to tell when the asthma is out of control, is an important area of disagreement between parents and physicians in the population studied. When a parent and physician aggree on this issue the parent is more likely to be successful in managing the child's asthma at home.

The relationship between the parent and physician is also important area of Disagreement in parent-physician pairs in this population. The roles for each are not

clear for the majority of parents and physicians studied. Most parents and physicians of children whose asthma was out of control are clear that the physician is more in charge, but think the other would disagree by saying they work together.

Satisfaction in the parent-physician relationship was also important. When the child's asthma is in "good control", there is no disagreement observed between the parent and physician, but when the child's asthma is out of control, the physician wants the parent more involved.

Delimitations

Twelve physicians and their pediatric patients with asthma were accepted for the study.

The physicians were accepted on a volunteer basis.

The geographic area in which the physicians were solicited is that area within a twenty mile radius of the researcher's home in Leverett.

The parents were also solicited on a volunteer basis.

Only one parent in each family was asked to participate in the study. Almost all the "primary care parents" who volunteered and participated in the study were mothers: only one was a father.

The parent participants were mostly white; a few were hispanic.

The patients were to be between the ages of one and twenty years.

The ashtma was to have been diagnosed at least one year prior to participation in the study.

Each physician had at least one patient whose asthma was out of control.

Limitations

Questionnaires were used to obtain sensitive information in relationships. While the intent was to be as objective as possible in collecting and analyzing the data, questionnaires do not leave room for elaboration that, for example, interviews might.

Interpretation of the findings in a causal-comparative method can conclude only that a relationship exists between Disagreement and control of a child's asthma, not the direction of causality. The researcher cannot know whether uncontrolled asthma in a particular child is the cause or the result of the Disagreement.

As the sample is not randomized, the study must be considered quasi-experimental. Internal validity might have been threatened if not all of the doctors had patients in the study whose asthma was out of control. Each doctor did, however, have at least one patient in the study whose asthma was out of control. This helps ensure that the findings in the study are due to the

variable of Disagreement, rather than differences between physicians.

Although the study population totaled 59 parent-physician pairs, there is not complete independence of observations, as the pairs came from only twelve physicians, each with one to eleven parents. Therefore, external validity is limited to the practices of the twelve physicians studied.

Recommendations for Practice and Education

Social support is essential for parents and children with asthma to help them meet the challenge asthma poses for family life. Support groups are recommended to give them a sense of empowerment through the opportunigy to share common experiences and to provide a pool of resources for problem solving. Support groups can be led by a motivated parent or by a mental health professional. It is not recommended that one of the health care providers lead the group, as the power imbalance is not conducive to genuine sharing of feelings and, because it is not always conducive to the participants taking charge for themselves.

Self-management education for parents and for children with asthma through group training has been shown to be effective improving asthma outcome, in the research literature. These groups can be led bythe

child's physician or another medical professional. In addition to information about asthma and its treatment and to training with the at-home procedures, the groups can provide an opportunity for an exchange of ideas between parents and medical professionals. Expression of disagreement should be encouraged, as we know it exists. It is only through the acceptance of differences that people can begin to negotiate a contract of committment to participation in a treatment plan. Physicians and other health care providers may also benefit from updated education on the changes in asthma treatment and prevention.

Clear communication between physicians and parents about management of a child's asthma is strongly urged in the effort to maintain "good control" of the child's asthma. Particularly, who does what, and when, needs to be clarified, for example, how the child and parent should judge when the symptoms are out of control, and when the parent and/or adolescent child should call the physician. A written contract between the pediatric patient, the parents, and the physician is strongly recommended, as verbal contracts leave too much room for ambiguity and misunderstanding. The contract should be re-evaluated and renegotiated as necessary.

Regularly scheduled meetings between the child with asthma, their parents or guardians, and the child's

physician, as often as they think necessary, may help prevent emergency visits. At these meetings, the persons involved can negotiate the contract for treatment at home, evaluate the child's progress, re-evaluate the treatment contracts, etc. The physician can educate parents and children in the office and offer information about resources available, for example, group programs, books about asthma.

Recommendations for Further Research

We know what some of the areas of Disagreement are between twelve physicians and parents of their pediatric patients with asthma. We also know some areas of parent-physician Disagreement that are related to control of the asthma for the children studied. It is recommended that investigations continue in the area of disagreement between parents and physicians of children with asthma. A replication of this study in other medical practices is warranted to see if the findings can be repeated. Another study might randomly select medical practices throughout the country, in order to be able to generalize the results.

A likely follow-up to this study would be to conduct interviews based on these findings, to check out the questions left unanswered because of the questionnaire style of data collection.

The researcher did not look at the relationship between type of parent-physician relationship and Disagreement. It would be important to know if some types of relationships are associated with parent success in managing the child's asthma at home. The researcher also did not look at how each subject's responses to the nine categories of questions were related to one another. For example, did one person or pair disagree to most of the questions and another person or pair disagree to few of the questions? These issues can be answered with further analysis of the data already obtained in this study.

APPENDIX A:

INTRODUCTORY LETTERS/CONSENT FORMS

39 Cider Mill Road
Leverett, Massachusetts 01054
May 22, 1990

Dear

As a doctoral student in Counseling Psychology in the School of Education at the University of Massachusetts, at Amherst, Massachusetts, I am requesting your support and participation in my dissertation research. I am interested in the management of asthma, and would like to investigate how parents and physicians think about childhood asthma. It is a study about their ideas, not about their knowledge. Several physicians and parents of their pediatric patients with asthma will be asked to participate. It is hoped that the findings will contribute to our knowledge about the process of physicians and parents working together to help children manage their asthma.

The study involves two questionnaires, essentially the same in content: one to be completed by the parents of the children with asthma, and one to be completed by the childrens' primary care physicians. If you agree to participate, I shall ask to send Parent Consent Forms and Parent Questionnaires to the parents of all your patients with asthma between the ages of two years and eighteen years, and who have been diagnosed with asthma for at least one year. When I have received the signed consent form and completed questionnaire from a parent, I shall then ask that you complete the Physician's Questionnaire for that parent's child with asthma. The confidentiality of all participants will be protected. In return for completing and returning a questionnaire, I would like to give the choice of one of the following two books about asthma (with your approval) to each participant:

1: The new, "pocket-sized" paperback edition of Children with Asthma: A Manual for Parents, by Thomas F. Plaut, Pedipress, 1989, or

2: Winning over Asthma, by Eileen D. Savage, Dolan Press, 1989.

Also, I will be happy to provide, to anyone who is interested, a summary of the research methodology and findings when the study is completed.

I would like to call you by telephone, in a few days, to ask whether you are interested and willing to participate in this study. It may be helpful for us to meet in person to further discuss the procedures involved, and to address any questions and/or concerns that you may have.

Thank you for your time and consideration.

Sincerely,

Pat Schumm-Rosen, M.S.
Graduate Student,
Counseling Psychology

William J. Matthews, Ph. D.
Chairperson, Dissertation Committee

29 Cider Mill Road
Leverett, Massachusetts 01054

PHYSICIAN CONSENT FORM

Dear Dr. _____,

Thank you for your interest in my research project. As you know, I am a graduate student in Counseling Psychology in the School of Education at the University of Massachusetts, at Amherst, Massachusetts. I am interested in the management of asthma in children, and I am requesting your participation in my doctoral dissertation research project. This study will explore how parents and physicians think about asthma. It is a study about ideas, not about knowledge. Several physicians and the parents of their patients with asthma will be asked to participate. It is hoped that the findings will contribute to our knowledge about the process of physicians and parents working together to help children manage their asthma.

This study involves two questionnaires, essentially the same in content: one to be completed by parents of children with asthma and one to be completed by the children's primary care physicians. If you agree to participate, I will ask to send Parent Consent Forms and Parent Questionnaires to the parents of all of your patients with asthma between the ages of two years and eighteen years, and who have been diagnosed for at least one year. When I have received the signed consent form and completed questionnaire from a parent I will ask that you complete the Physician's Questionnaire for that parent's child with asthma.

In order to protect the confidentiality of you and of your patient's family, identification numbers will be used in place of names. The same identification number will be used for both the Parent Questionnaire and the Physician Questionnaire for the same child. The researcher will see only the identification numbers, and neither physician nor parent will see or know one another's responses.

In order for the study to be successfull, it is important that you and your patient's family do not discuss the questionnaires with one another until both are sent back to me. If you have any questions at any time about the research procedures, please call me at (413) 548-9222, and I will do my best to answer your questions. Also, if you are interested, you may call or write me at the above home address and I will send you a summary of the research methodology and the findings when the study is completed.

There are no discomforts or risks expected by your participation in this study. You have the right to withdraw your consent at any time, without prejudice to you.
Please sign below, if you agree to participate:

I, _____agree to participate in the research project conducted by Patricia Schumm-Rosen, as described above. I understand that my consent to participate includes the participation of the parents of my patients with asthma.

_____ _____

Signed Date

University address of the researcher:

Patricia Schumm-Rosen
Counseling Psychology Program
School of Education
Hills South, Room 354
University of Massachusetts
Amherst, MA 01003

39 Cider Mill Road
Leverett, Massachusetts 01054

PARENT CONSENT FORM

Dear_____,

I am a graduate student in Counseling Psychology in the School of Education at the University of Massachusetts at Amherst, Massachusetts. I am interested in the management of asthma in children and I am writing to you with the permission and support of your child's physician, Dr._____, to request the participation of both you and Dr. _____ in my doctoral dissertation research project. This study will explore how parents and physicians think about asthma. It is a study about ideas, not about knowledge. Several physicians and the parents of their patients with asthma will be asked to participate. It is hoped that the findings in this study will be useful to parents and physicians, in their efforts to help their children manage asthma.

This study involves two questionnaires, essentially the same in content: one to be completed by a parent of the child with asthma and one to be completed by the primary care physician of the child with asthma. If you agree to participate in this study, Dr._____ will also participate, by completing the Physician's Questionnaire about your child's asthma. The study is designed so that the participation of both parent and physician are important. I am not looking for the same answers - simply, for your own ideas.

I ask that the parent who has primary adult responsibility for management or supervision of your child's asthma will sign the consent form and complete the enclosed questionnaire. If both parents or guardians take equal responsibility for management of the asthma, I ask that the persons involved choose only one of them to sign the consent form and complete the questionnaire, and to send both back to me at the above address at your soonest convenience.

In order to protect your confidentiality, an identification number will be assigned to your child's name. Your questionnaire will have this identification number on it, but not your name. I will then send your

identification number to Dr._____, who will be using the same identification number to complete the Physician's Questionnaire, but will never know how you have responded. Your name will not be used in any way, either during the research process or in the future. If you choose not to participate in the study, simply do nothing and the process will be discontinued.

In order for the study to be successful, it is important that you and your child's physician do not discuss the questionnaires until both are sent back to me. If you have any questions at any time about the research procedures, please call me at (413) 548-9222, and I will do my best to answer your questions. Also, if you are interested, you may call or write me at the above address and I will send you a summary of the research methodology and the findings when the study is completed.

There are no discomforts or risks expected by your participation in this study. You have the right to withdraw your consent and to discontinue your participation in the research procedures at any time, without any prejudice to you.

Please sign below, if you agree to participate:

I, _____agree to participate in the research project conducted by Patricia Schumm-Rosen, as described above. I understand that my consent to participate includes the participation of Dr._____, as described above.

_____ _____

Signed Date

University address of the researcher:

Patricia Schumm-Rosen
Counseling Psychology Program
School of Education
Hills South, Room 354
University of Massachusetts
Amherst, MA 01003

APPENDIX B

QUESTIONNAIRES

PHYSICIAN QUESTIONNAIRE

DATE:
Your identification number:_____
Your age:_____ Gender:_____M_____F
Type of practice: ____pediatric; ____family
Years in practice:
Percentage of your practice that are children with asthma:
Patient's identification number:
Primary care parent:
As compared with other patients in my practice, I know this patient:
(Check one) ___very well;___average;___not well.

INSTRUCTIONS: This is an investigation about ideas, not about knowledge. There are no right or wrong answers. The oddd numbered questions ask for your own ideas about asthma and its treatment for this particular patient. The even numbered questions ask for your guess about the ideas of the parent or guardian who has filled out the Parent Questionnaire (See top of page for identity). If you think you do not know this patient and/or her/his parent well enough to answer the questions, please answer as you woulld for most of your patients with asthma. THANK YOU.

Questions 1 through 10 ask you to RANK order your responses. Some questions are followed by only 5 choices, while others are followed by 6 or 8 choices. A ranking of "1" indicates your first choice of responses on a continuum, while the highest number indicates your last choice:
FIRST CHOICE 1..2..3..4..5-8 LAST CHOICE
Please rank every choice, i.e.: (3) A.
(1) B.
(2) C.

1. Please RANK order from 1 to 5 what you consider to be the most likely reasons this child has asthma.
(MOST LIKELY 1...2...3...4...5 LEAST LIKELY)
( ) A. Child's physiological make-up.
( ) B. Child's personality and/or individual psychological problems.
( ) C. Environmental irritants (i.e., pollution).
( ) D. Family problems.
( ) E. Other_____.

2. Please RANK order what you think this parent believes to be the most likely reasons this child has asthma.
(MOST LIKELY 1...2...3...4...5 LEAST LIKELY)
( ) A. Child's physiological make-up.
( ) B. Child's personality and/or individual psycholgical problems.
( ) C. Environmental irritants (i.e., pollution).
( ) D. Family problems.
( ) E. Other_____.

3. In your opinion, how likely are the following factors to "trigger" (bring on) asthmatic symptoms in this patient? Please RANK order your responses from 1 to 6.
(MOST LIKELY 1...2...3...4...5...6 LEAST LIKELY).
( ) A. Exercise.
( ) B. Upper respiratory infection.
( ) C. Pollutants.
( ) D. Allergy.
( ) E. Cold air.
( ) F. Emotions.

4. How do you think this parent would RANK the choices to Question #3?
(MOST LIKELY 1...2...3...4...5...6 LEAST LIKELY).
( ) A. Exercise.
( ) B. Upper respiratory infection.
( ) C. Pollutants.
( ) D. Allergy.
( ) E. Cold air.
( ) F. Emotions.

5. Please RANK order, from 1 to 8, how helpful you think the following approaches to treatment might be in controlling your patient's asthmatic symptoms.
(MOST HELPFUL 1..2..3..4..5..6..7..8 LEAST HELPFUL).
( ) A. Medication.
( ) B. Hospitalization.
( ) C. Desensitization (allergy shots).
( ) D. Avoidance of allergens.
( ) E. Decrease physical activity.
( ) F. Homeopathy or chiropractic.
( ) G. Individual psychotherapy for the child.
( ) H. Family or couples therapy.

6. Please RANK order how you think this parent would answer Question #5.
(MOST HELPFUL 1..2..3..4..5..6..7..8 LEAST HELPFUL).
( ) A. Medication.
( ) B. Hospitalization.
( ) C. Desensitization (allergy shots).
( ) D. Avoidance of allergens.
( ) E. Decrease physical activity.
( ) F. Homeopathy or chiropractic.
( ) G. Individual psychotherapy for the child.
( ) H. Family or couples therapy.

7. Please RANK order the following measures of "good control" of this child's asthma from most useful to least useful.
(MOST USEFUL 1..2..3..4..5 LEAST USEFUL)
( ) A. Number of hospitalizations per year.
( ) B. Number of school absences per year.
( ) C. Number of unscheduled visits to the physician's office or emergency room per year.
( ) D. Interference with usual activities of child and/or other family member(s).
( ) E. Peak flow chart.

8. Please RANK order how you think this parent would answer Question #7.
(MOST USEFUL 1...2...3...4...5 LEAST USEFUL).
( ) A. Number of hospitalizations per year.
( ) B. Number of school absences per year.
( ) C. Number of unscheduled visits to the physician's office or emergency room per year.
( ) D. Interference with usual daily activities of child and/or other family member(s).
( ) E. Peak flow chart.

9. Please RANK order what you think will be the most likely future course for this child's asthma.
(MOST LIKELY 1...2...3...4...5 LEAST LIKELY).
( ) A. This may be the last episode, for the rest of her/his life.
( ) B. Symptoms may continue, on and off, for another year or so, and then stop.
( ) C. She/he will probably outgrow the symptoms when she/he becomes an adult.
( ) D. She/he will have symptoms, on and off, for the rest of her/his life.
( ) E. She/he will probably outgrow the symptoms, at least for awhile, but the symptoms may return sometime later in life.

10. Hoow do you think this parent would RANK the choices to Question #9?
(MOST LIKELY 1...2...3...4...5 LEAST LIKELY)
( ) A. This may be the last episode, for the rest of her/his life.
( ) B. Symptoms may continue, on and off, for another year or so, and then stop.
( ) C. She/he will probably outgrow the symptoms when she/he becomes an adult.
( ) D. She/he have symptoms, on and off, for the rest of her/his life.
( ) E. She/he will probably outgrow the symptoms, at least for awhile, but the symptoms may return sometime later in life.

Questions 11 through 18 require ONE ANSWER ONLY. Please indicate the best choice with a CHECK MARK ( ).

11. To what degree do you think your patient's asthmatic symptoms interfere with usual daily activities? (CHECK ONE)
( ) A. The asthmatic symptoms do not interfere with either the child's or the family's usual daily activities.
( ) B. They occasionally interfere with the child's usual daily activities.
( ) C. They occasionally interfere with the activities of the child and at least one other family member.
( ) D. They often interfere with the child's activities.
( ) E. They often with the activities of the child and at least one other family member.

12. How do you think this parent would answer Question #11? (CHECK ONE)
( ) A. The asthmatic symptoms do not interfere with either the child's or the family's usual daily activities.
( ) B. They occasionally interfere with the child's usual daily activities.
( ) C. They occasionally interfere with the activities of the child and at least one other family member.
( ) D. They often interfere with the child's activities.
( ) E. They often interfere with the activities of the child and at least one other family member.

13. The following question concerns number of hospitalizations, emergency room visits, and/or unscheduled visits to the physician's office per year as indicators of whether or not the child's asthma is in "good control". How many of any combination of these per year might this patient have for you to consider her/his asthma to be in "good control"? (CHECK ONE)
( ) A. 0.
( ) B. 1 - 2.
( ) C. 3 or more.

14. How many hospitalizations, emergency room visits, and/or unscheduled visits to the physician's office per year do you think this parent woulld say is within the margin of "good control" for this child? (CHECK ONE)
( ) A. 0.
( ) B. 1 - 2.
( ) C. 3 or more.

15. Please indicate which of the following you think best describes your relationship with this parent as it relates to making decisions about treatment of the asthma. (CHECK ONE)
( ) A. The physician and the parent(s) and/or child with asthma make decisions about treatment of the asthma together.
( ) B. The physician makes most of the decisions.
( ) C. Parent(s) and/or child usually consult(s) with the physician and then makes(s) the final decisions.
( ) D. Parent(s) and/or child make(s) most of the decisions, based on a verbal or written contract with the physician.
( ) E. Parent(s) and/or child make(s) most of the decisions, without consulting the physician, and without a verbal or written contract.

16. Please indicate which of the following you think this parent would check to answer Question #15. (CHECK ONE)
( ) A. The physician and the parent(s) and/or child with asthma make(s) the decisions about treatment of the asthma together.
( ) B. The physician makes most of the decisions.
( ) C. Parent(s) and/or child usually consult with the physician and then make(s) the final decisions.

( ) D. Parent(s) and/or child make(s) most of the decisions, based on a verbal or written contract with the physician.
( ) E. Parent(s) and/or child make(s) most of the decisions, without consulting the physician, and without a verbal or written contract.

17. Please indicate which of the following most closely describes your attitude toward your relationship with this parent as it relates to making decisions about treatment of the asthma. (CHECK ONE)
( ) A. I would prefer the parent(s) and/or child to become more involved in the process of making decisions about treatment of the asthma.
( ) B. I would prefer the parent(s) and/or child to consult with me more in making decisions about treatment of the asthma.
( ) C. I am satisfied with our relationship as it is.

18. Please indicate which of the following you think best describes this parent's attitude about her/his relationship with you as it relates to making decisions about treatment of the asthma. (CHECK ONE)
( ) A. This parent would like more opportunity to become involved in making decisions about treatment of the asthma.
( ) B. This parent would prefer to consult with me more in making decisions about treatment of the asthma.
( ) C. This parent is generally satisfied with our relationship as it is.

Thank you for your assistance in completing this questionnaire.

PARENT QUESTIONNAIRE

Please RETURN within ONE WEEK to: Pat Schumm-Rosen
P.O. Box 424
Leverett, MA 01054

DATE:
Identification number:
Parent or guardian completing
questionnaire: ___Female ___Male
Age of Parent:_____Parent's Race:_____
Family Income Level: ____less than 11,000
___11,000-15,999 ___16,000-25,999 ___26,000-35,999
___36,000-44,999 ___45,000 or above
Child's Gender: ___Male ___Female Child's Race: ___
Child's Age:
Date of Diagnosis:
Number of Hospitalizations for asthma in the last 12 months:
Number of unscheduled visits to a doctor's office or emergency room in the last 12 months:

INSTRUCTIONS: This is an investigation about ideas, not about knowledge. There are no right or wrong answers. The odd numbered questions ask for your own ideas about your child's asthma and its treatment. The even numbered questions ask for your guess about the ideas of your child's doctor for the asthma. Please answer the questions as best as you can. THANK YOU.

Questions 1 through 10 ask you to RANK order your answers. This means you will order the choices numerically from your first choice to your last choice. Some questions are followed by only 5 choices, while others are followed by 6 or 8 choices. Use a "1" to indicate your first choice, in response to a question, and progressively higher numbers to indicate second, third, and fourth choices, etc., with the highest number to indicate your last choice:

FIRST CHOICE 1..2..3..4..5(-8) LAST CHOICE

Please rank every choice, for example:

(4) A.
(1) B.
(2) C.
(5) D.
(3) E.

1. Please RANK order, from 1 to 5, what you consider to be the most likely reasons your child has asthma.
(MOST LIKELY 1...2...3...4...5 LEAST LIKELY)
( ) A. Child's physiological make-up.
( ) B. Child's personality and/or individual psychological problems.
( ) C. Environmental irritants (i.e., pollution).
( ) D. Family problems.
( ) E. Other_____.

2. Please RANK order what you think your child's doctor believes to be the most likely reasons your child has asthma.
(MOST LIKELY 1...2...3...4...5 LEAST LIKELY)
( ) A. Child's physiological make-up.
( ) B. Child's personality and/or individual psychological problems.
( ) C. Environmental irritants (i.e., pollution).
( ) D. Family problems.
( ) E. Other_____.

3. In your opinion, how likely are the following factors to "trigger" (bring on) asthmatic symptoms in your child? Please RANK order your responses from 1 to 6.
(MOST LIKELY 1...2...3...4...5...6 LEAST LIKELY)
( ) A. Exercise.
( ) B. Upper respiratory infection.
( ) C. Pollutants.
( ) D. Allergy.
( ) E. Cold air.
( ) F. Emotions.

4. How do you think your child's doctor would RANK the choices to Question #3?
(MOST LIKELY 1...2...3...4...5...6 LEAST LIKELY)
( ) A. Exercise.
( ) B. Upper respiratory infection.
( ) C. Pollutants.
( ) D. Allergy.
( ) E. Cold Air.
( ) F. Emotions.

5. Please RANK order, from 1 to 8, how helpful you think the following approaches to treatment might be in

controlling your child's asthmatic symptoms.
(MOST HELPFUL 1..2..3..4..5..6..7..8 LEAST HELPFUL)
( ) A. Medication
( ) B. Hospitalization.
( ) C. Desensitization (allergy shots).
( ) D. Avoidance of allergens.
( ) E. Decrease physical activity.
( ) F. Homeopathy or chiropractic.
( ) G. Individual psychotherapy for the child.
( ) H. Family or couples therapy.

6. Please RANK order, from 1 to 8, how you think your child's doctor would answer Question #5.
(MOST HELPFUL 1..2..3..4..5..6..7..8 LEAST HELPFUL)
( ) A. Medication.
( ) B. Hospitalization.
( ) C. Desensitization (allergy shots).
( ) D. Avoidance of allergens.
( ) E. Decrease physical activity.
( ) F. Homeopathy or chiropractic.
( ) G. Individual psychotherapy for the child.
( ) H. Family or couples therapy.

7. Please RANK order the following measures of "good control" for this child's asthma from most useful to least useful.
(MOST USEFUL 1...2...3...4...5 LEAST USEFUL)
( ) A. Number of hospitalizations per year.
( ) B. Number of school absences per year.
( ) C. Number of unscheduled visits to the doctor's office or emergency room per year.
( ) D. Interference with usual daily activities of child and/or other family member(s).
( ) E. Peak flow chart.

8. Please RANK order how you think your child's doctor would answer #7.
(MOST USEFUL 1...2...3...4...5 LEAST USEFUL)
( ) A. Number of hospitalizations per year.
( ) B. Number of school absences per year.
( ) C. Number of unscheduled visits to the doctor's office or emergency room per year.
( ) D. Interference with usual daily activities of child and/or other family member(s).
( )E. Peak flow chart.

9. Please RANK order what you think will be the most likely future course for your child's asthma.
(MOST LIKELY 1...2...3...4...5 LEAST LIKELY)
( ) A. This may be the last episode, for the rest of her/his life.
( ) B. Symptoms may continue, on and off, for another year or so, and then stop.
( ) C. She/he will outgrow her/his symptoms when she/he becomes an adult.
( ) D. She/he will continue to have symptoms, on and off, for the rest of her/his life.
( ) E. She/he will probably outgrow the symptoms, at least for awhile, but they may return sometime later in life.

10. How do you think your child's doctor would RANK the choices to Question #9.
(MOST LIKELY 1...2...3...4...5 LEAST LIKELY)
( ) A. This may be the last episode, for the rest of her/his life.
( ) B. Symptoms may continue, on and off, another year or so, and then stop.
( ) C. She/he will outgrow her/his symptoms when she/he becomes an adult.
( ) D. She/he will have symptoms, on and off, for the rest of her/his life.
( ) E. She/he will probably outgrow the symptoms, at least for awhile, but they may return sometime later in life.

Questions 11 through 18 require ONE ANSWER ONLY. Please indicate the best choice with a CHECK MARK ( ).

11. To what degree do you think your child's asthmatic symptoms interfere with usual daily activities? (CHECK ONE).
( ) A. The symptoms do not interfere with either my child's or our family's usual activities.
( ) B. Occasionally interfere with my child's activities.
( ) C. Occasionally interfere with the activities of my child and at least one other member of our family.
( ) D. Often interfere with my child's activities.
( ) E. Often interfere with the activities of my child and at least one other member of my family.

12. How do you think your child's doctor would answer Question #11? (CHECK ONE)
( ) A. The symptoms do not interfere with the activities of either child or family.
( ) B. Occasionally interfere with child's activities.
( ) C. Occasionally interfere with activities of child and at least one other family member.
( ) D. Often interfere with child's activities.
( ) E. Often interfere with activities of child and at least one other family member.

13. The following question concerns number of hospitalizations, emergency room visits, and/or unscheduled visits to the doctor's office per year as indicators of whether or not the child's asthma is generally in "good control". How many of any combination of these per year might your child have for you to consider her/his asthma to be in "good control"? (CHECK ONE)
( ) A. 0.
( ) B. 1 - 2.
( ) C. 3 or more.

14. How many hospitalizations, emergency room visits, and/or unscheduled visits to the doctor's office per year do you think your child's doctor would say is within the margin of "good control"? (CHECK ONE)
( ) A. 0.
( ) B. 1 - 2.
( ) C. 3 or more.

15. Please indicate which of the following you think best describes your relationship with your child's doctor as it relates to making decisions about treatment of the asthma. (CHECK ONE)
( ) A. The doctor and the parent(s) and/or child with asthma make(s) decisions about treatment of the asthma together.
( ) B. The doctor makes most of the decisions.
( ) C. Parent(s) and/or child usually consult(s) with the doctor and then make(s) the final decisions.
( ) D. Parent(s) and/or child make(s) most of the decisions, based on a verbal or written contract with the doctor.
( ) E. Parent(s) and/or child make(s) most of the decisions, without consulting the doctor, and without a verbal or written contract.

16. Please indicate which of the following you think your child's doctor would check to answer Question #15. (CHECK ONE)
( ) A. The doctor and the parent(s) and/or child with asthma make(s) the decisions about treatment of the asthma together.
( ) B. The doctor makes most of the decisions.
( ) C. Parent(s) and/or child usually consult(s) with the doctor and then make(s) the final decisions.
( ) D. Parent(s) and/or child make(s) most of the decisions, based on a verbal or written contract with the doctor.
( ) E. Parent(s) and/or child make(s) most of the decisions, without consulting the doctor, and without a verbal or written contract.

17. Please indicate which of the following most closely describes your attitude toward your relationship with your child's doctor as it relates to making decisions about treatment of the asthma. (CHECK ONE)
( ) A. I wish there were more opportunity in my(our) relationship with the doctor for parent(s) and/or child to be more involved in making decisions about treatment of the asthma.
( ) B. I would prefer the doctor to make more of the decisions about treating the asthma and expect less from parent(s) and/or the child with asthma.
( ) C. I am satisfied with our relationship as it is.

18. Please indicate which of the following you think best describes your child's doctor's attitudes about her/his relationship with you as it relates to making decisions about treatment of the asthma. (CHECK ONE)
( ) A. The doctor would prefer to make more of the decisions her/himself.
( ) B. The doctor would prefer parent(s) and/or child to make more of the decisions.
( ) C. The doctor is generally satisfied with our relationship as it is.

Thank you for your assistance in completing this questionnaire.

APPENDIX C:

TABLES

TABLE 1

DISAGREEMENT IN PERCENTAGES

		OBS	PTPR	PHYPR	PTAC	PHYAC
1	Causes	1.8	0	0	1.8	1.8
2	Triggers	3.5	0	0	0	1.8
3	Treatment	3.5	0	0	3.5	0
4	Qual. Control	11.5	0	0	1.9	15.4
5	Future	5.6	0	0	7.4	5.4
6	Severity	42.1	20.3	17.9	31.6	39.3
7	Quan. Control	52.6	32.2	15.8	42.1	47.4
8	Type Relat.	44.6	6.9	10.5	37.5	44.6
9	Sat. Relat.	22.8	10.2	33.3	24.6	26.3

TABLE 2

RELATIONSHIP BETWEEN FREQUENCY OF DISAGREEMENT AND CONTROL OF THE CHILD'S ASTHMA

	OBS	PTPR	PHYPR	PTAC	PHYAC
	p	p	p	p	p
Causes	1	1	1	1	1
Triggers	2 *	2	2	2	2
Treatment	3 NS	3	3	3 NS	3
Qual. Control	4	4	4	4	4 NS
Future	5 NS	5	5	5 NS	5 NS
Severity	6 NS	6 NS	6 *	6	6 NS
Quan. Control	7 NS	7 NS	7 NS	7 *	7 NS
Type Relat.	8 NS	8	8	8 NS	8 NS
Sat. Relat.	9 *	9 NS	9 NS	9 *	9 NS

P < 0.10, * p < 0.05, ** p < 0.01

TABLE 3

LAYOUT OF DATA

Substantive Areas	Parent Self (TYPE 1)	Parent Physician (TYPE 2)	Physician Self (TYPE 3)	Physician Parent (TYPE 4)
1. Causes of Asthma	Q1	Q2	Q1	Q2
2. Triggers of Symptoms	Q3	Q4	Q3	Q4
3. Approaches to Treatment	Q5	Q6	Q5	Q6
4. Qualitative Measures of "Good Control"	Q7	Q8	Q7	Q8
5. Expectations of Future Course	Q9	Q10	Q9	Q10
6. Severity Level	Q11	Q12	Q11	Q12
7. Quantitative Measure of "Good Control"	Q13	Q14	Q13	Q14
8. Type of Pt-Phy Relationship	Q15	Q16	Q15	Q16
9. Satisfaction with Relationship	Q17	Q18	Q17	Q18

<u>Types of Disagreement</u>

Observed	Type 1 vs. Type 3
Parent Perceived	Type 1 vs. Type 2
Physician Perceived	Type 3 vs. Type 4
Parent Accuracy	Type 2 vs. Type 3
Physician Accuracy	Type 1 vs. Type 4

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